

















# AMERICAN **Autumn 1990** REHABILITATION



**Rehabilitation Dentistry**  
**Mutual Help Groups**

**Placement**  
**Disability Management**



# 70 Years of Hope 70 Years of Success

## *The state-federal vocational rehabilitation program*

*Nell C. Carney, Commissioner  
Rehabilitation Services Administration*

From a glimmer of hope to a successful and comprehensive rehabilitation program, from a \$750,000 allowance to a \$1.5 billion annual budget, from a demonstration project to a formula based nationwide program, the state-federal vocational rehabilitation (VR) program spans seven decades of providing hope, training, employment, opportunity, independence, and empowerment for millions of Americans with disabilities. Offering full integration and participation for people who might otherwise have been forced to stand merely in the shadows of life, this successful partnership between the state and federal government has withstood political, social and economic change. Its value to people with disabilities and its productive impact on the nation are undisputed.

Following a model used in Massachusetts in 1918, the federal government launched a demonstration program in vocational rehabilitation in 1920. The earliest programs were directed toward returning industrially injured workers to the labor force. Borrowing methodology and techniques from the veterans programs, which were designed to assist wounded World War I soldiers, the first VR activities leaned toward guidance and counselling and vocational training. But, from the beginning, the presence of hope has been prevalent in rehabilitation — hope by the disabled individual that positive change could occur and



hope by the service provider that the process could affect change.

In the 1930's, the state-federal VR program struggled for permanence. After the passage of the Social Security Act and other legislation directed toward employment opportunities for disabled Americans, the Congress began to look more favorably at the state-federal partnership. By 1940, the program was not only made permanent but was expanded to include physical restoration services, including hospitalization and surgery, and people with mental disabilities were added to the list of disabled Americans who could receive VR services.

Something of a revolution took place in 1954 when rehabilitation training and research were added to the program. Professionals could now be

trained under federally supported university programs. Research which would bring a new era of enlightenment to the field could now be conducted. There was renewed hope and promise that quality of services would improve and expanded opportunities would be created for Americans with disabilities. The hope and promise became a reality — quality of service rose, opportunities expanded, and the field of rehabilitation was elevated to a level of professionalism among the elite classes in human services professions.

It was also in this period that the severely disabled population was recognized for priority in the receipt of services. New hope and promise for people with severe disabilities brought greater expectations which translated into expanded programs — additional funding, more opportunities.

In the 1960's, the state-federal programs continued to expand, and it was in this decade that the rehabilitation facilities amendments and Projects With Industries (PWI) were added to the statutory language. The RSA facilities staff grew from 3 to 23 during this period. Facilities became a stronger partner within the service delivery network, and this expansion of services benefited more people.

The next decade changed the course of rehabilitation history in America. The Rehabilitation Act of 1973 not only returned the programs to sound basic principles but also expanded them to comprehensive levels of services that created hope and expectation where none had existed. The new legislation allowed disabled people to pursue dreams of opportunity and employ-

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The weakest ink is better than the strongest memory.

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Cover Photo: Wheelchair transfer is accomplished by dental patient, who is shown with Dr. Doris Stiefel, author (left), and Bill Kelly of the Department of Rehabilitation Medicine, University of Washington. See article on page 14.

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# A Research Based Innovative Placement Program

David Vandergoot, Ph.D.  
Victoria Wenzel, M.B.A.

*It is frequently heard that research does not address the everyday constraints that face practitioners, or that research is irrelevant to the needs of people with disabilities and professionals. However, this article will show how research findings can be integrated into a service delivery system that meets the needs of both these groups. Vandergoot in 1986 and 1987 conducted an extensive review of research literature that related rehabilitation service system factors to placement. The findings were used to design a system to create more job opportunities for people with disabilities. Following is a description of this service model.*

The Innovative Placement Program, which is being evaluated over a 3-year period through a grant from the National Institute on Disability and Rehabilitation Research, is managed by the Research & Training Institute of the National Center for Disability Services, a comprehensive vocational rehabilitation facility. The goal is to place people with disabilities into the work force as directly as possible by using technology and community resources to the fullest. A case manager provides or coordinates all services from the point of intake through placement, including follow along. The model includes:

- job-seeking skills training enhanced by group methods and peer support;
- the place-train approach using community and business sites for service delivery locations;
- functional assessment methods that link a person's abilities to specific training and job performance standards;
- applications of new technology, such as labor market information available in computerized databases and rehabilitation engineering innovations; and

- creative use of community resources to overcome problems such as lack of accessible and affordable transportation.

Hard to place people are referred from local state vocational rehabilitation offices. Over a 3-year period, some 100–120 people will be served.

The project's services were organized around Baldrige's (1972) systems view of human services organizations which contains five interdependent components, including services and technology, clientele, staff, administration, and external linkages. These components are used to outline research findings which substantiate the rationale for the Innovative Placement Program.

## Services

Services refer to all the techniques and strategies available to help people obtain jobs. Services should provide an edge to them by minimizing the chance factor so prevalent in determining labor market outcomes (Rothstein, 1980). Effectiveness of these services can be measured by relating how each contributes to placement, *which is the ultimate goal*.

Evaluation services are frequently the first offered and include formal

procedures such as medical, psychological and work evaluations to determine if a person is suitable for rehabilitation and, if so, to identify factors useful for vocational planning and service delivery. However, research which has explored the relationship of typical evaluation findings to placement suggests that the value of many accepted practices is questionable. For example, Stolarski (1985) found that standard psychological test findings were not useful in discriminating eventual placement outcomes. One study correlated vocational competency assessments made by work evaluators with the training and employment outcomes experienced by clients (Cook, 1983). Although there was a significant relationship between the assessments and whether clients completed a training program, there was *no relationship* to their eventual employment status. Therefore, the Innovative Placement Program has eliminated much of what is typically found in standard evaluation programs.

After evaluation, vocational training typically is given which can be offered in many different forms, including education, skills development and work adjustment. It is assumed that there is a logical progression that connects evaluation findings and training to the type of job a person gets. However, the empirical evidence that training achieves this is not encouraging. Chun & Growick (1983) conducted a study of congruence between training and eventual placements. The findings were that only half of the jobs were related to training, which was similar to that of earlier studies (Bowman & Micek, 1973; Dalton & Latz, 1978). However, when train-



ing is related to employment success rather than on a targeted job goal, positive results occur. Worrall and Vandergoot (1982) found that while training generally was related to successful outcome, *on-the-job training was most strongly related to eventual employment.*

A new approach to services has evolved recently, and is based on community-referenced instruction (Snell & Browder, 1986). This strategy minimizes transfer of learning and removes elements of the rehabilitation process that are not job related. Most resources and services are used at the placement site rather than prior to placement, as is done in traditional adjustment programs. An experimental evaluation of a community-based demonstration project serving 254 clients showed a 44 percent placement rate in competitive jobs. Twenty-two months after starting the program, 31 percent of the experimental group were competitively placed, compared to 19 percent of the controls. More of those from the control group were placed in sheltered settings. Benefit cost analyses were also favorable (Kerachsky, Thornton, Bloomenthal, Maynard & Stephens, 1985).

**A**n evaluation of a supported work project operating at 17 sites, although not including an experimental design, had similar results. Two-thirds of all participants completed the program which led to placement of 81 percent working. It was estimated that program costs would be paid back in less than 2 years (Bailis, Jones, Schreiber & Burstein, 1984). Thus, community-based training and service delivery is emphasized in the Innovative Placement Program.

Another service technique receiving attention is the development of individualized placement plans which have been related to improved placement rates (Zadny & James, 1979). An experimental study to explore the extent of this relationship found that placement planning, if not actually producing more placements, had important results (Hansen, 1983), including:

- Time to placement was cut in half.
- Congruence between placement and training was improved significantly.
- Clients had more realistic expectations about the labor market.
- Counselors became more involved in placement.

The key ingredient may be *active counselor involvement* required to mon-

itor the plan; this may be supportive for the client during the difficult times while job searching. Evidence for the value of counselor involvement was found in a study done by Vandergoot, Maiman-Reich & Murphy (1983). Various approaches were tried to increase the motivation of clients during job searching. Motivators included counselor contact, which served as well as providing cash rewards contingent on job search behaviors. Formal placement planning and active counselor involvement in the placement process is central to the Innovative Placement Program.

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An intervention that is becoming more prevalent is rehabilitation engineering. Mallik & Yuspeh (1979) reported that rehabilitation engineering applications were useful in creating job opportunities for 79 of 116 clients who were previously rejected for services because of the severity of their disabilities. Similarly, Tooman (1982) found that using a team to provide engineering services placed more people at about the same costs as a traditional placement approach. Technological applications appear to be a key factor in placement for people with physical disabilities, and these will be used as needed by the Innovative Placement Program.

The research literature indicates that once a person is working, post-placement services are needed to assure suc-

cess. A survey of placement specialists ranked *job coaching, awareness training for employers and co-workers and followup services* as the most effective strategies to help people maintain jobs (Crimando, Belcher & Riggan, 1986). This study also explored why people lost their jobs. Recasting the findings into categories of productivity skills and social skills, it appears that productivity problems accounted for about 38 percent of failed placements, while social problems accounted for about 23 percent. Another study also found that productivity and social problems, alone or combined, could explain why people with severe disabilities lost their jobs (Hanley-Maxwell, Rusch, Chadsey-Rusch & Renzaglia, 1986). Both of these problems are behavioral ones that can be resolved with the appropriate behavior change strategy. Rehabilitation professionals can redeem the value of their prior services by monitoring post-placement performance and intervening as necessary to teach new ways of being productive or relating to others.

An important way counselors can help is by working with employers on behalf of clients. A study of 142 employers who had previous experience with rehabilitation programs (Young, Rosati, Vandergoot, 1986) *confirmed that they valued the following services most:*

- providing applicants with relevant occupational skills;
- providing clients with appropriate interpersonal skills;
- teaching clients how to conduct a thorough job search;

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- providing pre-screened applicants; and,
- providing followup services, including work adjustment, personal/social adjustment and opportunities for phone consultation.

- *The Functional Assessment Rating System (FARS)*, which is a computer-based case management tool that allows a counselor to prepare an employment profile using all known information about the client. This is

Situational assessments are used if questions remain regarding which jobs would provide suitable opportunities. The case manager arranges for these at as many job sites as possible. These provide direct evidence about a person's ability to achieve at specific jobs and minimize the risk of making inappropriate placements.

The placement plan concludes the assessment process. All information is reviewed at a meeting attended by the client, his/her significant other(s), the referring counselor, the project case manager, and the *Employment Services Specialist (ESS)* who assists in job development. The ESS professional works with Projects With Industry (PWI) employers to identify potential job openings. The plan includes the range of jobs targeted as appropriate, all services needed, where in the community the services are to be provided, the people responsible for service delivery, and target dates for completion of all services.

The second phase of the program is to provide community-based experiences designed to accomplish the targeted placement outcome. Clients participate in a job finding club to learn job seeking and job adjustment skills. They work together to find appropriate community opportunities for training and employment as specified in the placement plan. As community sites are found, an array of services are applied to accommodate the functional limitations of clients. The outcome of this second phase is a training and/or work site that is truly integrated. Job coaching is recommended when needed. Only when there are no suitable training sites in the community are services given in a rehabilitation setting.

The program provides rehabilitation engineering and technology services, when applicable, by a team consisting of a technology specialist, an occupational therapist and a rehabilitation engineer. All three participate in the evaluation. Depending on findings, the specialist locates aids and devices which overcome a person's limitations in the work

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*Even more striking was the disparity between employer needs and rehabilitation response in the area of followup services.*

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Although these services were in demand, the employers felt their needs were not fully met. For example, although 60 percent of employers said they used a variety of placement services, over 90 percent felt they could have used more. Even more striking was the disparity between employer needs and rehabilitation response in the area of followup services. Only about one-third of the sample was able to use these services while about 90 percent of employers needed them. This suggests that rehabilitation agencies are falling short. Or, a more positive view is that there are more opportunities to serve employers than we realize. Meeting their needs will most likely have direct impact on getting jobs.

One study found that employer ratings of client performance after 1 month on the job were the best predictors of eventual success (Liebert, 1984). Employers can quickly tell whether problems are likely to result in a failure. Staying involved with employers and clients during the initial employment period could be a useful strategy for ensuring successful placements and is central to the Innovative Placement Program.

In summary, the service delivery system begins with an intake interview of client's medical, educational and vocational history. Findings are used to identify strengths and weaknesses relevant to employment that need to be verified by appropriate evaluation procedures. A vocational assessment is then conducted. This process responds to questions raised during the intake. Specific procedures include:

used to plan additional evaluation procedures, contribute to a service plan and serve as a baseline against which to compare a person's progress through the rehabilitation process.

- *The General Aptitude Test Battery and the Apticom*, which are used to measure aptitudes corresponding to those in the *Dictionary of Occupational Titles*.

- *The Attitude Toward Disabled Persons Scale (ATDP)*, which is used to determine a person's attitude toward his/her own disability. Research at the Research and Training Center found that the ATDP predicted need for counseling during rehabilitation. Efforts are made to ensure that people have a positive attitude about themselves before they assume employment.

- *Transfer-of-Skills Analysis*, which is used with people who have a work history that includes skilled and semi-skilled jobs, to identify skills from past jobs that have not been lost due to an impairment. These are reviewed for their placement potential and are targeted during the job search should the person want to use them.

Following this, an employability profile is developed by the case manager. *Work Readiness Assessment Checklists*, developed by the Research and Training Institute, document the person's employment strengths and weaknesses. The details and usefulness of the checklist are described later. Next, a local labor market analysis, using the employability profile, is done to identify a range of jobs that match the profile or that could be achieved with varying degrees of training.



and/or training site. If none is found or if an aid or device needs additional modifications, the engineer designs and fabricates what is needed. The aid or device is thoroughly evaluated with adjustments made until it provides the functional capacity required.

Every client receives follow-along services to accommodate needs and concerns at the work or training site as well as in the home. For those in transitional and supported placements, job coach services are recommended until performance standards are met. For those in competitive jobs, follow along is provided as needed. As part of the placement plan, the case manager arranges for follow along prior to placement. Follow-along services are also offered to employers to ensure that their needs are met and that all possible reasonable accommodations are made for their workers. The original placement plan projects a 6-month period of follow-along services, which may or may not be revised and extended on the basis of the person's work performance. Six months is selected because successful work adjustment should be achieved, in most cases, within this time.

*The Minnesota Satisfaction and Satisfactoriness Scales* are used to assess work adjustment. After both the employee and employer indicate that this has satisfactorily occurred, the career plan, modeled after the original placement plan, is developed. This details short- and long-range goals and activities the client can pursue to upgrade his/her career as desired. When appropriate, the employer is asked to participate in this planning to assure the worker about the potential for future career development. This plan suggests what personal, employer and community resources can be used to further the individual's career.

### **Tailoring the Innovative Placement Model**

This general model must be adapted to the unique needs of people with disabilities. Fortunately, people seek vo-

cational rehabilitation services primarily for employment purposes (Gregg, Miller & Roberts 1976; Murphy & Salomone, 1983).

People with disabilities are similar to other Americans in that the same demographic factors relate to labor market outcomes for both groups, such as education, age, work history, and family structures. Dunn (1981) reports the following findings from the work force in general that may be instructive for rehabilitation practices:

- The more occupations at which a person is willing to work, the better the chances of finding a job.
- An occupational goal often changes during the job search (Ullman & Gutteridge, 1973), illustrating the need for flexibility in the labor market and questioning the adherence to one goal or a limited set of job goals. It further illustrates how information obtained during a job search can be used to modify original goals.
- When the economy has been favorable, job seekers needed at least three interviews before a job was obtained (Ullman & Gutteridge, 1973). An unfavorable market would require more interviews. Clients need to have appropriate expectations and support during the job search.
- The more extensive the job search, the greater the eventual salary, job satisfaction and career progress (Ullman & Gutteridge, 1973).

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*Skilled interviewing performance by clients may be our greatest tool in overcoming negative employer attitudes.*

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• Applicants displaying greater interviewing abilities received higher salary offers (Ullman & Gutteridge, 1973). Skilled interviewing performance by clients may be our greatest tool in overcoming negative employer attitudes.

Kundu (1985) found that people with a work history prior to and after receiving a disability were more likely to

become placed (94 percent) than those who worked only after their disability (71 percent) or only before their disability (60 percent). Those without a work history were the least likely to be placed. The importance of work history was also documented by Fraser, Clemmons, Trejo and Temkin (1983).

It is difficult to know how knowledge of work history can be used for placement purposes. Skills learned on previous jobs might still be within a person's capacity. Past employers may be good job lead sources. One study used a transferability of skills analysis of work histories of over 200 people to develop worker-trait profiles (Underwood, 1981). These profiles were used to develop a statistical model to predict those likely to become employed. A nearly 80 percent correct rate of prediction was obtained. The same study tested an alternate method for developing the worker-trait profile based on work evaluator recommendations. Although almost equally correct predictions were made, the researcher showed that considerably fewer resources were needed to generate the worker-trait profiles using the transferability of skills analysis. As described earlier, the Innovative Placement Program will employ this approach to identify residual skills to be considered during occupational planning.

Work readiness assessment is done formally or informally with almost all

clients. However, rehabilitation counselors have a difficult time identifying it (Kneipp, Vandergoot & Lawrence, 1980). It is a difficult construct that has much appeal but for which suitable objective measures do not yet exist. Recently, attention has been paid to disincentives to work inherent in rehabilitation and disability related programs



(Berkowitz, 1980; Walls, Maisson & Werner, 1977; Walls, 1982). The evidence suggests that people who participate in benefit programs rarely obtain jobs and are rarely work ready.

To aid both the client and the case manager in determining work readiness, the Innovative Placement Program uses *Readiness Planning Checklists* at different stages of the re-

families and others in the clients' support networks are asked to assist in the search. The purpose of these strategies is to teach people to be as responsible for their own placement as possible. However, this does not release the case manager from active placement involvement. The case manager provides ongoing counseling and support from the point of intake to post-placement.

a technology services evaluation is conducted.

A *Site Assessment*, which is a thorough review of the work/training site, is also conducted by the case manager and/or ESS. The grounds and buildings are inspected to see if barriers exist which impede access. If there are barriers, the technology team develops an approach that reasonably accommodates the person and is manageable to the employer.

Counselors may tend to view placement as part of service delivery rather than as the goal of services. It has been found that counselors may refer clients for placement to turn them around from failure to success (Crystal, 1981). This approach is hardly the concept of a pre-screened job applicant pool employers expect and which is an essential part of vocational rehabilitation marketing strategies.

Another study revealed differences in expectations reported by counselors and clients regarding goals of services, types of services and accountability for accomplishing services (Murphy & Salomone, 1983). People came to a rehabilitation agency for vocational purposes and expected help to get a job. Counselors on the other hand, did not expect to get involved with job placement. Clients have indicated that they feel neglected by their counselors during the job search (Murray, 1981). Studies repeatedly show that counselors spend relatively little time on placement (Zadny & James, 1977).

The Innovative Placement Program requires that, along with the assistance of the ESS, the client and case manager be responsible for placement activities. Continued case manager contact ensures case continuity and enables the case manager to provide encouragement, maintain client motivation and reduce anxiety during job searching.

#### **Administrative Factors**

Program policy can be designed to facilitate placement. Zadny & James (1979) discovered these relationships:

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*Studies repeatedly show that counselors spend relatively little time on placement (Zadny & James, 1977).*

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habilitation process. The first checklist assesses the client's medical, psychological and vocational situation. The checklist is then used as a planning tool to determine needed services and issues to be addressed along with a tentative time schedule. Finally, after readiness for working is apparent, a second checklist, measuring readiness to job search, is used to serve as a mutually written agreement between the case manager and client, thus enabling the client to share in the placement process with the case manager's guidance. It is used to plan and monitor all services that are required to move the client toward successful placement.

People with disabilities are an excellent placement resource, and over half find their own jobs (Zadny & James, 1976; Fraser, 1978). This strength can be enhanced by careful planning, flexibility and support. Ugland (1977) found that by providing clients with an information support system, their job finding activities and outcomes were greatly enhanced beyond that of another group of clients which did not receive support.

In view of these findings, the Innovative Placement Program equips people with effective job seeking skills through a job finding club. The case manager and clients work together to find appropriate community opportunities for training and employment as specified in the placement plan. The

#### **Staff Factors**

Not much research is available that relates staff characteristics, functions and interactions to placement outcomes. Although placement is the goal of many rehabilitation programs, one study revealed there are many staffing approaches, suggesting there is little consensus as to how to best get the job done (Vandergoot & Swirsky, 1980). This Innovative Placement Program requires the case manager to be responsible for the entire service process, but also uses special placement resources. Clients are referred to a *Placement Assistance Program* supported by PWI funds from the Rehabilitation Services Administration. This program is staffed by *Employer Service Specialists* who do job development and use a subcommittee of employers to recommend job leads. These supports help develop community-based placements. The case manager and ESS share employer development activities and work site visits.

After community sites are identified as potential training and employment opportunities, the ESS and case manager conduct a *Critical Items Analysis*. This is an abbreviated job analysis procedure to determine if any potential tasks at the work or training site will be difficult for a person to do, given his/her functional limitations. If such problems are found,



- Requiring specific individualized placement plans was related to higher rates.

- Placement rates achieved by counselors tended to follow agency-set goals; also, encouraging local labor market contacts was related to higher placement rates.

Smits & Emener (1980) surveyed counselors and administrators of several state rehabilitation agencies to assess views the two groups had concerning constraints that limit the time counselors spend on placement even though it is a high priority (Zadny & James, 1977). Ability to develop placements was not considered in performance appraisals. Therefore, placement was perceived as a low priority. Paperwork was too time consuming and administrators had mixed feelings about the value of placement specialists. Several recommendations emerged from these findings. Obviously, placement needs to become a real priority, which should be reinforced by setting performance expectations and actual consequences for meeting or not meeting placement goals.

Another study by Pretz (1980) concluded that emphasizing placement issues does show a relationship to placement outcomes. Over 140 counselors and supervisors of 22 field offices of state agencies were surveyed. The offices were divided into high and low functioning units on the basis of placement productivity. Important perceptions included the following:

- Establishing goals for caseload sizes and placements was associated with high productivity.

- Agency standards for time spent on placement were associated with fewer unsuccessful closures.

- Performance evaluation based on placement expectations was linked to increased productivity.

- High producing offices had counselors who felt they were knowledgeable about placement and the local labor market, while counselors from less productive offices felt more knowl-

edgeable about preparing clients for work readiness.

- Participative administrative approaches and clear policy communication were found more frequently at the productive offices.

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*Obviously, placement needs to become a real priority, which should be reinforced by setting performance expectations and actual consequences for meeting or not meeting placement goals.*

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In response to these findings, the Innovative Placement Program is using a computer-based information system that tracks events of the entire rehabilitation process. This system permits the case manager to record a great deal of information with a minimum of effort. It is clear to the case manager that placement is the priority and all activities are justified in terms of how they contribute to placement outcomes. All staff meet weekly to make decisions about how to manage the resources of the project.

### External Linkages


Probably the most important connections rehabilitation programs must make is *with employers*. Referral sources and other community agencies are important also. Although scant, research done on PWI programs which initiate employer advisory councils (Vandergoot & Swirsky, 1982; Pretz, Daggett & Koren, 1982) found that although the number of placements does not seem to increase during the first year or two, the quality of placements in terms of wages and retention rates shows improvement. Other outcomes showed that councils provided additional resources such as funds, new training equipment, community-based training, and information pertinent to local labor markets. Another study found that facilities which did not adopt the advisory council model received few of these re-

sources, while those that applied the model received substantial contributions of resources (Vandergoot & Swirsky, 1982).

The Innovative Placement Program links applicants to existing openings in

the local labor market. The PWI program has an extensive network of over 300 employers. The families and others in the support networks of applicants are asked to assist in the search process. In addition, local placement networks of rehabilitation professionals are used to increase the labor market contacts. The objective of all is to access as many resources and contacts as possible.

### Summary

The Innovative Placement Program is a deliberate attempt to integrate research and practice, not only in the design of the service model, but in other ways as well. The management information system is designed to organize client, service and research data in a way that does not burden the case manager. The system is computerized and, eventually, all reports will be generated from information in the database. All research analyses will be done from the database as well. The service staff meet regularly with research staff to share impressions and plan for refinements of the program. Finally, the advisory board has representatives from referral sources, employers, service personnel, and research staff. Thus, the program is not only an attempt to use research but a demonstration of how research and service professionals can maintain ongoing collaborative relationships. 



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# Organizational Commitment: The Key to Successful Implementation of Disability Management

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Lauren B. Gates, Ph.D.*

When John Salter, a 50-year-old experienced railroad worker, sustained a severe tear of his right rotator cuff (muscles surrounding the shoulder) swinging down from the locomotive, he was frightened about what a period of disability might mean to him and his family. But in a bad news/good news scenario, he was grateful that his accident had occurred after the company had enacted a disability management/return to work program. He knew many railroaders who had been retired on permanent disability following an accident such as his. Even with an operation to repair the tear the best he could hope for was a long recovery. At worst, he could expect pain, limitation of motion, weakness, and sufficient atrophy of the shoulder muscles so that he could never again have sufficient shoulder strength to pull himself up onto the locomotive. He was reassured that with a return to work program now in effect, some kind of light work would be found for him. The months following injury were a period of increasing disillusionment for John as each department that he thought had responsibility to return him to work found some excuse to turn his case over to another unit. In the end, he opted for retirement like so many of his predecessors, fearful that he might lose all financial security if he pressed any longer for the option of return to work. In John's situation, the disability management promise proved to be a paper giant missing the organizational commitment needed to activate its potential. This fatal flaw is

not unusual in programs and policies established by large scale organizations, and disability management is no exception to that rule.

Disability management is currently receiving widespread attention from employers, trade unions, policy makers, and social service providers as the problems faced by workers with disabilities and the impact of disability on the workplace become more clearly identified and understood. The ability to implement effective disability management programs, however, remains problematic for most, in part because successful disability management requires that attention be paid not only to workers with disabilities but also to their work organization and its relationship to the community. The authors believe that neglecting this second organizational component sabotages both the worker's efforts at job maintenance or return and the organization's interest in productivity and cost containment. Although there are many factors that determine the outcome of a disability management program, the results of a study carried out at the Workplace Center of the Columbia University School of Social Work suggest that unless an organization can assimilate disability management into all relevant aspects of its policies and practices, the disability management initiative will fail. This article will focus on aspects of an organization that affect successful implementation of a disability management program.

Disability management is an early intervention effort, the purpose of which is to assist a newly disabled worker in successful job maintenance or return to work. Current statistics show

that the likelihood of return to work for employees after the onset of disability is low. Half of those who experience lost time following the onset or worsening of disability while at work will drop out of the workforce permanently if they do not return within 5 months (Carbine et al., 1989). The reasons for unemployment are not limited to the health problems caused by the disability. Research shows that a wide range of problems arise from the onset of disability and can act as barriers to return to work (Gates, Taler & Akabas, 1989). These problems include meeting financial obligations with significantly reduced income, coping with changing family dynamics and responsibilities as a consequence of disability, overcoming the emotional impact of disability, negotiating with the worksite for transitional employment or permanent job accommodations, establishing new vocational goals when necessary, and maneuvering through the medical and social welfare community to obtain the assistance needed for return to work.

While the needs of the disabled worker are foremost, disability management programs also help the organization. They do so because they can reduce the impact of disability on the worksite by helping to contain costs associated with disability, minimize the negative effects of disability on organizational productivity and main-

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tain employee morale and work group competence. It is estimated that disability costs in income maintenance benefits to the employee and medical care expenses can account for up to 6 percent of a company's budget and these costs will continue to rise by as much as 10 percent over the next year (Carbine et al., 1989). The costs of replacement hiring and training, and the indirect costs of lowered productivity due to lost days at work and low employee morale are also considerable. Further, workforce demographics are changing (Johnston, 1987). The workforce is both aging and dwindling, reflecting the demographics of the baby boom generation and the lower birth rates between 1965 and 1976, and disability among employees can be expected to increase in the future. It is to the employer's advantage, therefore, to establish the means of maintaining workers with disability, many of whom comprise the skilled, knowledgeable labor force. Finally, effective disability management can assist the employer in preparing for the regulations likely to follow passage of the Americans with Disabilities Act.

### **A Model for Understanding the Role of the Organization in Disability Management**

One way to understand how the organizational context affects the success of the disability management program is to assess aspects of the organization that promote or constrain program activity. Kurt Lewin's model of force field analysis (Deutsch, 1968) provides a framework for such an assessment. Lewin described a state of organizational equilibrium as a time when, in relation to a particular issue, the forces promoting change are in balance with the forces restraining change. For change to occur the promoting forces must increase, the restraining forces decline or some combination of movement of each must occur. In considering disability management, when the forces promoting effective disability manage-

ment outweigh the forces constraining disability management, the resulting equilibrium is expressed as successful return to work or job maintenance by the disabled workers. Conversely, when constraining forces outweigh promoting forces the resulting equilibrium is expressed as unemployment or underemployment of workers with disabilities.

The Early Intervention Project of the Workplace Center has helped identify aspects of organizations that act as the forces promoting or constraining program activity. These forces are derived from the ecosystem in which the organization operates. The building blocks of the program are a bio/psycho/social model of assessment, early intervention and a case management strategy that utilizes an ecosystem approach to problem solving. First, the program takes a bio/psycho/social approach which recognizes that disability is only a small element in loss of employment. The assessment helps newly disabled workers return to work by identifying barriers to return in all aspects of the individual's life, including financial, family, health and medical care, or work-related problems. Second, intervention is immediate following onset or worsening of disability in order to avoid the development of a mind set that changes a worker into a self-perceived disabled person unable to work. Early intervention seeks to identify and solve problems before they become insurmountable (Akabas, 1986; Gleason, 1986; Lewis & Mama, 1987). Third, case management in an ecosystem context facilitates the process because the case manager serves as liaison and advocate linking the worker with all relevant systems and their resources in the family, community and worksite and negotiating needed accommodations (Gates, Taler & Akabas, 1989). Having identified the complexity of this approach, a primary objective of the Early Intervention Project has been to document how individual needs and organizational and community policy and practice interact to affect outcome.

Funded by the National Institute on Disability and Rehabilitation Research (NIDRR) and carried out in collaboration with the Human Resources Development Institute (HRDI) of the AFL-CIO, the program was implemented in New York City, Baltimore, St. Paul, St. Louis, Houston, and the state of Montana. Newly disabled workers were identified, administered an assessment interview and offered assistance to help cope with problems encountered during the period of disability. The Workplace Center monitored service delivery and collected and analyzed the data set. Some 256 disabled workers participated in the program, representing 15 unions and 28 insurance carriers.

The data which demonstrates the importance of the organizational context comes from the Center's training for case managers and assistance to them in solving unexpected problems. Although data is qualitative, content analysis of study records reveal patterns supporting the significance of the reported observations.

Three categories of organizational factors and/or community systems that promote or constrain effective disability management are revealed by the analysis. These include:

- organizational commitment to the disability management program;
- responsiveness of the worksite to disabled workers; and
- investment in disability management over time.

The remainder of this article will discuss each of these.

### **Organizational Factors that Promote or Constrain Disability Management**

*Organizational Commitment to Disability Management.* The first step towards establishing an effective disability management program is the visible commitment of top management to the process. Commitment is expressed in several ways. First, the employer needs to develop an explicit policy for disabled workers. For example, the position of the employer towards providing



accommodated work, temporarily or permanently, needs to be specified. Results of the study show that most disabled workers (73 percent) want to return to work, but feel unable to perform their jobs in their current condition. Yet, most (80 percent) perceive that their employers are "somewhat to very inflexible" when it comes to making needed job accommodations. Over two-thirds of program participants (68 percent) assume that they must be able to perform their jobs at 100 percent before they return and, therefore, they wait until they feel able to perform all functions of their jobs. In some instances, however, program case managers negotiated early accommodated

monitoring of their participation was implemented. The program never became a priority and was not given the attention it needed to take hold in the organization.

Another study of the Workplace Center, which evaluated disability management activity by Employee Assistance Programs (EAP's), identified some of the specific organizational policy areas of importance (Akabas & Krauskopf, 1989). These include:

- the length of time a disabled employee's job will be guaranteed;
- the amount of salary replacement provided by disability coverage;
- the availability of accommodated "light duty"/transitional work;

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*With a well formulated and well publicized policy, workers are likely to seek assistance from the employer to facilitate their return.*

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return for disabled workers. The work-sites tended to be very receptive. This lack of communication, and consequent lengthened period of disability, results in an organizational problem that can be reduced and even eliminated by an explicit and broadly distributed policy that commits the workplace to reinstate disabled workers through the use of necessary accommodations. With a well formulated and well publicized policy, workers are likely to seek assistance from the employer to facilitate their return. Supervisors, or other personnel who would authorize such accommodation, are also more likely to believe it is within their power (and responsibility) to change work requirements. When the policy is tied to performance appraisal of supervisors, the positive results are even greater. At one site the executive supported implementation of the disability management program, but did nothing except instruct managers to proceed. Lower level managers and supervisors were not part of the decision, and explicit guidelines were not provided to define the extent of action they could take. No

- the degree to which formal transitional employment arrangements dovetail with disability salary replacement policy; and
- the budget to which salary replacement is charged.

These policies must be designed to provide incentives for employees to return and supervisors to cooperate in that process. For example, linking the availability of "light duty" to encourage early return while charging income maintenance costs to the relevant supervisor's budget can be a powerful assurance of early return to work. Clearly, gaining some work from an employee is superior to paying the person the same amount to stay home and make no contribution to the work of the organization. A worker who can be accommodated is better served than one who languishes home in deepening depression. A "win-win" situation is created in which employee and supervisory interests are meshed and the organization emerges as the prime beneficiary.

Commitment by top management is demonstrated by assigning resources to the disability management program.

Perhaps most important is the allocation of staff time and availability of training. At some sites, the program was administered by social work professionals; at others, the program was run by benefits officers or union staff who lacked professional training. Where professional staff administered the service, delivery was enhanced, thereby also improving outcome. Professional staff (which would include rehabilitation counselors, although none were involved in the present project) were better equipped to elicit the needed information during the intake process, had a better grasp of the types of services necessary to remediate a particular problem and knew where in the organization and community they were available. In organizations that did not commit funds for professional staff, training was an alternate, but inadequate, allocation of resources. Training prepared those assigned to administer the intake interview, but they needed a backup consultant to compensate for the skills and power they lacked to harness organizational and community resources and to negotiate policy implementation.

Staff assigned to the program must have not only appropriate skills but sufficient time allocation to fulfill program responsibility. At all study sites disability management responsibilities were added to personnel's existing workloads. This set up a conflict for the case managers. Their inclination was to do the work with which they were familiar and where the expectations and criteria for evaluation were known. Additionally, in some cases, their co-workers were not supportive because co-workers perceived that they would have to pick up the slack left by those working on the program. Supervisors also faced a dilemma. Even if they knew that top management supported disability management, they also knew that the productivity of their departments could not be jeopardized. Supervisors tended, like case managers and co-workers, not to make the program a priority. Managerial com-



mitment is meaningless without specific staff and time allocation.

When top management makes a visible commitment, it "authorizes" changes in the organizational structure which are needed to support the disability management activity. Study results show that communication among departments is one of the most important structural adaptations needed. In most organizations, disparate departments like medical, human resource/

management use their status to network in the community. The study of the role of EAP's in disability management (Akabas & Krauskopf, 1989) enumerated welcomeness measures such as providing barrier free access; providing new or modified equipment; negotiating changes in job productivity requirements, job design, job location, or work schedule; providing a transitional work program; offering a formal procedure for temporary work accom-

workers often do talk to their doctors about what their jobs involve (87 percent) but do not go the next step to discuss returning to work in a modified form (27 percent). The employing organization can influence return to work by discussing rehabilitation with the treating physicians and by informing doctors about the requirements of the patient's job and of the possibility for accommodated work. Here, linkage among the medical department, whoever authorizes medical care payments and the disability case manager contributes a useful organizational structure. Second, case managers must be familiar with agencies that help disabled workers with the problems encountered after the onset of disability. Having a good understanding of programs and agencies that provide financial assistance, including knowledge of eligibility for public assistance, is a requisite for case managers. The Early Intervention Program study shows that nearly all program participants experienced financial problems. Over 80 percent said their financial situation had been affected at least moderately, and over 90 percent reported they had less money post disability.

Other agencies that respond to personal or disability related problems such as self-help or counseling groups, health service organizations (e.g., Cancer Care or the Multiple Sclerosis Society) and rehabilitation services are also important. Most employing organizations have the potential for stronger ties to community agencies because they and their employees contribute significant funds through United Way campaigns. These ties provide both an avenue for case managers to become informed concerning community services and the power to make demands on these resources in meeting the needs of workers with disabilities. This is particularly relevant when workers are represented by trade unions which have representatives stationed at the United Way.

The disability managers also need ties to the benefit providers whether the em-

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*When employers were perceived as inflexible, disabled workers also felt that it was unlikely they would be able to return to work.*

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personnel, health promotion, benefits, training, rehabilitation, workers' compensation, affirmative action, and risk management may be involved in assisting disabled workers. Case managers require formal connections with other departments to function effectively. For example, at one site the case managers required assistance from the social service department. A formal referral process provided case managers with a step-by-step procedure for identifying cases for referral and for making and maintaining contact with the social services department so that social service could be easily accessed. Training on how to make a referral was also provided to the case managers. Disability management was promoted by these structural changes that formalized linkages within an organization and specified the division of labor among units with complimentary responsibilities.

*Responsiveness of the worksite to disabled workers.* Worksite responsiveness to the disabled worker is the degree to which the worksite itself can meet the disability related needs of the newly disabled worker. Two aspects to worksite responsiveness include those services and accommodations which suggest the "welcomeness" of the worksite and the degree to which the organization and those involved in disability

modation; providing a role for disabled employees and their supervisors in job accommodation; and offering retraining programs when necessary. Early Intervention Program participants confirmed the need for many of these accommodations but perceived their employers as "unlikely" to make needed accommodations (44 percent). When employers were perceived as inflexible, disabled workers also felt that it was unlikely they would be able to return to work. Once again, we see evidence that organizational factors impede successful outcomes.

So too, the more community ties the employing organization develops, the better the referral mechanisms and, thus, the level of service received by the disabled worker.

First, case managers need to have ties with the medical and rehabilitation community. Research results show that the single most important factor that determines when, or if, a disabled worker returns to work is the return to work date set by the physician (Gates, Taler & Akabas, 1989). Physicians, however, often set the date without an understanding of what an individual's job involves. Consequently, some return before they are ready, while others stay out longer than necessary. The current study results show that disabled



ployer is self insured, a participant in a collectively bargained health welfare plan or is insured by a private insurance carrier. They must also be knowledgeable about available benefits. Finally, working directly with unions is valuable because it helps to build trust among disabled employees. Unions are viewed as advocates of the workers' interests and, therefore, union support for the program can motivate worker participation.

*Investment in disability management over time.* At outset, programs need time to gear up, establish policy and procedures and train staff. Monitoring and record keeping systems must be set in place. Study results show that existing forms often do not collect organizationally relevant information. Forms are needed to gather enough information to fashion appropriate intervention and to track individuals throughout the period so that it is possible to evaluate program effectiveness. Because of the complexity of establishing a disability management program, to observe positive outcomes requires further patience. While reduced lost time may occur quickly in some cases, other program impact may not be immediately evident. Then, it takes an additional period to assess how well the worker has been able to readjust to his/her job. Without long-range commitment it is not possible to carry out the longitudinal evaluation the authors have found is essential to confirm program effectiveness. So too, time is necessary to neutralize the forces restraining potential effectiveness of a disability management program within its organizational context and to promote forces that will encourage the cultural change needed to achieve worksite "welcomeness" for newly disabled employees. Without that organizational commitment our work suggests that a disability management initiative will be washed away with the tide.

## Conclusions

Based on the study outcomes, the following recommendations are offered:

- Explicit disability management policy and procedures should be set in place stating employer position toward salary replacement, job accommodation, transitional employment, budgetary responsibility, and vocational retraining when necessary. Where a union represents some of the covered employees, these policies should be negotiated jointly.

- Top level managers should include all management levels in developing the program to insure their understanding of the objectives and enhance their commitment to its implementation.

- Organizational commitment must be highly visible and involve allocation of significant resources of staff and time. Job descriptions should reflect tasks performed.

- Implementation by professional staff whose priority is the disability management team program assures that the fullest range of services will be within the network.

- Formal coordinated channels of communication need to be established among all departments involved in the disability management activity. A disabled worker should never be lost in the system. If assistance is needed from a department other than disability management, clear procedures for accessing that assistance must be in place.


- The employer must develop a climate of welcomeness that involves on-site services and accommodations for disabled workers.

- Supervisors need to be trained and provided with incentives to facilitate work return for disabled workers.

- Disability managers need to develop extensive ties with community resources. Resource books and procedures for how to establish contact must be available.

- Procedures for involving physicians in the return to work process must be established.

- Procedures for involving benefit providers and unions in the return to work process must be established.

- Management must allow a reasonable amount of time before evaluating program effectiveness. 

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# The Role of Rehabilitation Dentistry

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*Dentistry is an essential health discipline that contributes materially to the rehabilitation of people who are physically, mentally and medically compromised. The goal of rehabilitation dentistry is to restore and maintain the form, function and aesthetics of the dentofacial complex in order to help the individual attain his or her optimum level of physical function and social interaction. The importance of achieving and maintaining good oral health in people with disability is an aspect of rehabilitation that is only gradually gaining due recognition.*

People with disability face many problems in obtaining adequate dental care both in terms of daily oral hygiene and routine professional treatment. Physical barriers, financial limitations, poor motivation, and lack of qualified care providers are some of the difficulties that must be overcome.

To enable people who are disabled to participate in oral health services requires a concerted effort by many different rehabilitation disciplines. In this process, the other rehabilitation professions must develop a greater awareness of dental problems and dental professionals must learn to work in close coordination with members of the rehabilitation team. Such interaction will enhance the climate for successful rehabilitation, resulting in effective consumer education, better trained professional and nonprofessional caregivers, efficient clinical services, and, ultimately, the improved health and function of the disabled individual.

## Oral Health Problems

Disabling conditions frequently are associated with severe oral disease and dysfunction of the craniofacial complex. Multiple etiological factors play a role; some are inherent in the disability,

and others are untoward side effects. For example, the chromosomal abnormality of Down syndrome is associated with a high susceptibility to severe early-onset periodontal disease and premature loss of teeth in affected individuals (Reuland-Bosma & van Dijk, 1986). People with neurological and neuromuscular disorders, such as cerebral palsy, mental retardation and closed head injuries are prone to salivary incontinence (drooling), and severe bruxing (tooth grinding) habits that may result in excessive wear of teeth and injury to the temporomandibular joint (Richmond, Rugh, Dolfi, et al., 1984). Trauma to the dentition is of concern in people with seizure disorders. Severe weight loss, as in cancer, or loss of muscle tone, due to stroke, or other neuromuscular disorders may have adverse effects on the ability to wear dentures.

Drug-induced oral changes are of particular significance in the etiology of dental disease in disabled people. The effects of medication may be specific as in the case of Dilantin caused hyperplasia (abnormal increase in number of normal cells) of the gum tissue, or more general such as the head and neck manifestations of tardive dyskinesia

(late appearing involuntary movement) associated with antipsychotic medications. Reduction in salivary secretion by prescribed medications is of significant concern. Over 400 drugs have been identified as causing hyposalivation and xerostomia (dry mouth) (Sreebny & Valadini, 1987). Common medications in this group include antidepressants, antipsychotics, sedatives, hypnotics, antihistamines, anticholinergics, antiparkinsonism agents, antihypertensives, and diuretics. Reduced salivary flow greatly increases the risk for dental caries, particularly gumline decay, periodontal disease, yeast infections, and other oral lesions. The adverse effects of xerostomic medications were substantiated in a recent comparative study of subjects with and without mental illness (Stiefel, Truelove, Menard, et al., 1990).

The significance of preventing dental disease and maintaining oral health in people with disability cannot be overemphasized. Oral disease caused by dental neglect and the ensuing need for extensive treatment may place individuals who are severely disabled at serious additional medical risk. For people with major chronic medical disorders, advanced dental disease and its required treatment may have life-threatening consequences. Complex dental treatment resulting from lack of regular dental care increases costs, time lost from work, and impedes the rehabilitation process. For many people with disability, the oral cavity takes on critical importance in terms of psychological significance and physical function. The mouth has been termed the lifeline for the person who is disabled, the center of the per-



sonality in the absence of one or more functioning faculties (Kimmelman, 1989). The mouth may be the only part of the body over which the person retains voluntary control and the jaws and teeth may serve as the only functioning extremity. Every effort must therefore be made to save the natural teeth. If the natural dentition is lost, the person with a severe physical or mental impairment may not be able to manage a dental prosthesis to aid in eating, verbal communication, device-activated communication, and independent management of other tasks. Edentulism (having no teeth) is no longer acceptable to disabled people and their families. The disabled population has the same expectations regarding a functioning dentition as the nondisabled population.

### Access to Dental Care

Although in recent years the oral health of the population as a whole has improved significantly, people with disability continue to have serious dental problems and remain underserved in dental care.

A recent Dental Education in Care of the Disabled (DECOD) study of 106 RSA-supported rehabilitation agencies and organizations serving people with functional disabilities in Washington, Alaska, Oregon, and Idaho revealed significant dental needs. Of 77 groups responding, 88.3 percent stated their clients had unmet dental treatment needs, which suggests ongoing oral and dental disease. Financial factors were identified as a barrier to care by 86.6 percent of responding agencies, 63.4 percent cited barriers directly associated with the disability (i.e., can't find a dentist trained to work with disabled patients, difficulty with transportation to a dentist who can treat them, lack of motivation by their general caregiver). Fear of dental procedures was identified as a barrier to care by 34.1 percent of respondents, substantially higher than the prevalence of 20 percent reported for dental fear for the population at large

and, very likely, a reflection of lack of regular dental care and poor past dental experiences. The large majority, 80.2 percent, of the agencies stated it was important or very important for dentists to have specialized training to meet the unique needs of their clients (Stiefel, Truelove & Mandel, 1990).

Similar barriers to dental care are evident in other areas of the United States. In a survey of five regional centers for people with developmental disabilities in California, almost 50 percent of responding parents reported difficulties, including locating dentists, transportation and payment for care for their disabled children. Problems in accessing dental care tended to be associated with less frequent dental care and an extraction at the last dental visit, again suggesting unchecked dental disease (Finger & Jedrychowski, 1989).

Facilitating access to dental services for the person with disability requires support at all levels, including locating appropriate care providers, assisting with transportation or arranging for mobile dental services, determining availability of financial resources, and overcoming fear and anxiety. Rehabilitation counselors, therapists and case workers can provide valuable assistance in the coordination of dental care for people who are severely disabled.

The majority of people with disability can be treated in the regular dental office. A number of communities have listings of dental practitioners who are available to treat people with disability. These directories usually include such pertinent information as dentists' specialty and experience in treating patients with disability and office wheelchair accessibility (Stiefel, Shaffer & Bigelow, 1981; Siegal, 1986). Inquiries regarding the availability of a referral directory should be addressed to the local State Dental Association. People with complex conditions should be served by care providers who have had appropriate advanced training and are sensitive to the needs of special patients. A growing number of dentists and dental hygienists have gained ex-

perience treating people with disability either as part of their regular dental training, through residency programs or an advanced level course, such as the DECOD Program at the University of Washington, Seattle, WA. To meet the needs of disabled people who are not ambulatory, an increasing number of dental practitioners have mobile dental equipment and make house calls or visits to long-term care facilities (Casamassimo, Coffee & Leviton, 1988).

Finding financial resources and low-cost dental services can be a major challenge to the patient and the patient's counselor. Benefits for dental care under the Medicaid system vary from state to state and Medicare does not cover routine dental procedures. In some areas, dentists have agreed to participate in reduced fee programs or donate their services through projects such as DDS (Donated Dental Services) developed by the National Foundation of Dentistry for the Handicapped. Other sources for low-cost care are dental schools with special patient care programs and community clinics (Stiefel, Truelove & Mandel, 1984; Porter & Casamassimo, 1986). Additional resources worth exploration include fraternal groups and benevolent organizations. Young disabled patients may qualify for financial assistance from the Grottoes of North America, a Masonic order whose major philanthropic thrust is in this specific area of care.

Patients with disabilities may have difficulty in complying with scheduled dental appointments. Those who have not had regular dental care or have had

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unpleasant dental experiences may be fearful and reluctant to see the dentist. The availability of a caseworker or other support person to accompany such patients to the office for initial visits provides the support necessary to facilitate fear reduction. Over time, with appropriate behavior modification and quality care, fearful patients often become excellent dental patients.

## Patient Assessment

The mouth is an integral part of the body and dental treatment can affect and be affected by the patient's general physical and mental status. A thorough health history is an important prerequisite to safe treatment. For the patient with a physical or mental disability, it is particularly important to gain full information about problems or limitations that impact dental care. Areas of special concern include allergies, heart defects, prosthetic joints, and conditions that necessitate pro-

phylactic antibiotics prior to dental treatment. Knowledge of major systemic disorders such as diabetes, infectious diseases and current medica-

help assure treatment in a safe, systematic and expeditious manner.

Effective communication with the patient and/or responsible person is a

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*Consultation by the dentist with the patient's physician, counselor and other members of the rehabilitation team will help assure treatment in a safe, systematic and expeditious manner.*

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tions may dictate modifications in the delivery of dental care.

A disability profile should be part of the dental workup. It should focus on disability-related limitations and requirements, including etiology and time of onset, ability to tolerate proposed dental treatment, communication deficits, special positioning needs, indications for adaptive aids, support persons and the legal guardian. Consultation by the dentist with the patient's physician, counselor and other members of the rehabilitation team will

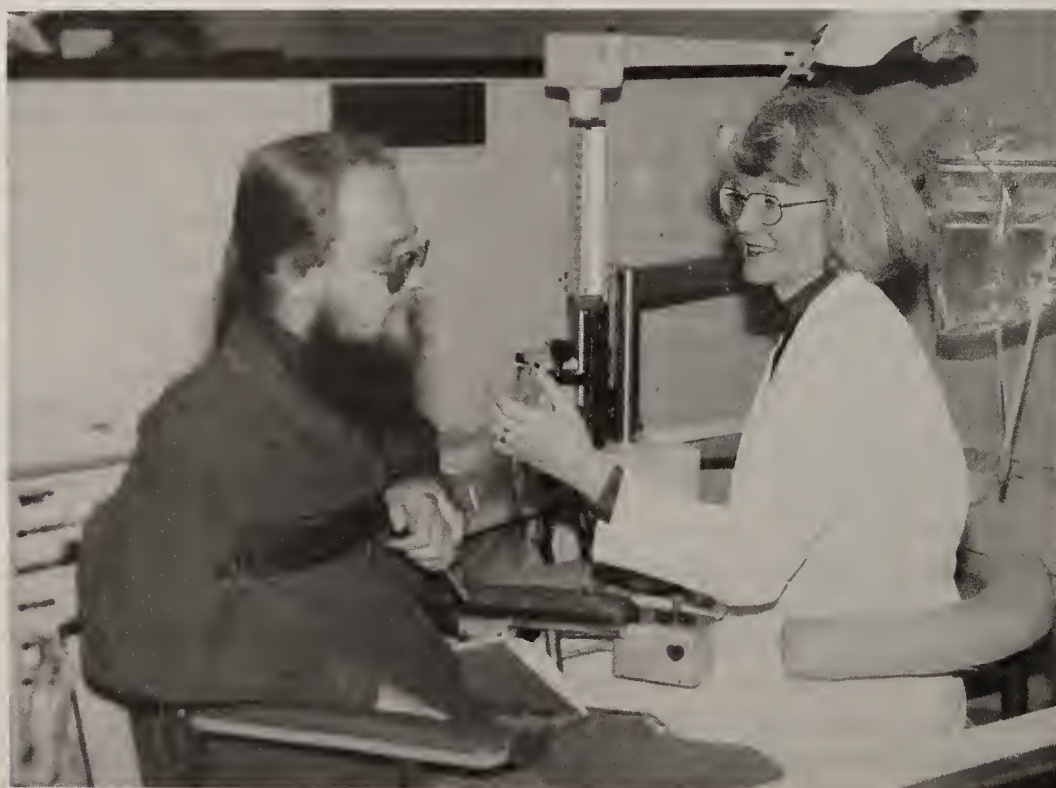
key component in patient assessment and management. For example, the person who is profoundly deaf may require the presence of a sign language interpreter. Those with mental disabilities (mentally retarded, psychiatric diagnosis, brain injured) or language deficits require a responsible person available to provide the patient's medical, dental and social history.

## Preventive, Restorative and Rehabilitation Dental Care

Dental caries and periodontal disease are largely preventable through daily oral hygiene and through periodic professional care. Many people with disability have physical or mental impairments that limit them in effectively performing oral hygiene procedures. They may be completely dependent on others for daily home care which unfortunately tends to be a low priority task for direct caregivers. Compliance in providing oral personal hygiene needs to be assured through staff inservice training reinforced at frequent intervals.

The high incidence of dental disease in people with disability warrants frequent mouth screening evaluation by daily caregivers and regular professional care. More frequent dental recall visits are often necessary and may need to be as frequent as every 3 months.

Advances in dental treatment methods hold considerable promise for improving the oral health of people with disability. Newer preventive therapies using disease-specific antimicrobial agents have proven effective and useful as adjuncts to professional dental care.



*Patient participates in research study on oral health and spinal cord injury (funded by the National Institute on Disability and Rehabilitation Research) at the DECOD Clinic, University of Washington.*



For people who are disabled, the usual protocol of application of such agents may need to be modified. Thus, a recent study supported by a grant from the National Institute on Disability and Rehabilitation Research has shown that, in lieu of oral rinsing, a mouthwash of 0.12 percent chlorhexidine gluconate (Peridex® Procter & Gamble) can be successfully applied to the teeth with a sponge swab (Toothette, Halbrand, Inc.) and when applied once daily in this manner, resulted in significant reductions in plaque and gingivitis (Stiefel, Truelove, Chin, et al., 1990). The study involved 80 adults with severe physical and mental disabilities who participated at 11 different rehabilitation settings, including long-term care facilities, supported employment and independent living. The protocol was well accepted by subjects and staff. Improved dental health was positively correlated with improved appearance, smile and mouth odor. People who reported good physical health tended not to have dental problems, to rate quality of life highly, to report improvement in smile, and to perceive no adverse effects from the teeth (Stiefel, Truelove, Chin, et al., 1990).

For people at high risk for dental disease, particularly dental caries, daily use of topical fluoride is also recommended, with the protocol of choice depending on the patient's condition and ability to empty the mouth (Yamagata, Stiefel & Horike, 1983).

While the dental operator remains the place of choice for extensive treatment, the advances in mobile dental equipment make onsite care an attractive alternative for routine diagnostic and preventive services for people with severe disabilities. Thus, oral screening examinations and professional cleaning of the teeth can be readily conducted in group homes, independent living centers and supported employment workshops. Similarly, oral hygiene procedures can be effectively incorporated into the daily schedule at group residences and supported work situations with monitoring by counselors or nursing staff.



*Instruction on oral care is given to patient by dental hygienist of the DECOD Program at the University of Washington.*

The construction of adaptive oral devices requires close collaboration of health disciplines including occupational therapy, orthotics, biomedical engineering, and dentistry. These devices can significantly enhance the level of independence of people with impaired function of the upper extremities. People who are quadriplegic may require a bitestick to perform many tasks. To preserve the health and function of the teeth and orofacial structures these appliances should be custom fabricated. They should provide

full occlusal contact and distribute the biting forces over the maximum area of tooth surface (Mulligan, 1983; O'Donnel, Yen & Robinson, 1985).

A variety of adaptive aids can also be used to foster independence in the performance of daily oral hygiene. These range from an elaborate commercially available appliance such as the Sunbeam Dental Care System for the Disabled (Northern Electric Company), developed by the University of Mississippi (Fitchie, Reeves, Comer, et al., 1988), to simple items such as rubber



balls, bicycle grips, wooden spoons, and rods that serve to enlarge or extend handles on tooth brushes and floss holders.

Patients with limited manual dexterity may also benefit from use of advanced types of rotary electric tooth brushes, such as the Interplak® instrument. For patients with swallowing defects, who are at risk for aspiration of fluids, toothbrushes with suctioning devices are available; Plak-Vac (Trademark Corporation) and Vac U Brush (ora genics) are two examples.


Another area of interest is the increasing use of tooth colored restorative materials that allow for aesthetic and relatively economic restoration of lost tooth structure. In addition, the ad-

Although dental and dental hygiene students usually receive an introduction to special patient care as part of their basic education, their preparedness to treat more severely disabled patients in community and nontraditional settings is generally limited (Cohen, LaBelle & Singer, 1985; Stiefel, Truelove & Jolly, 1987).

A need for postgraduate training in rehabilitation dentistry is evident. Based on more than 10 years of experience by the DECOD Program at the University of Washington, it appears that a range of training options must be offered. Training opportunities should include the self-instructional mode, short didactic and clinical participation

physical therapists from the Department of Rehabilitation Medicine demonstrate wheelchair transfer techniques, vocational counselors discuss psychosocial issues of disability, physiatrists lecture on various disabling conditions, nutritionists present concerns in nutrition, and speech pathologists provide dental professionals with basic information on speech and swallowing disorders. Furthermore, the inclusion in these courses of instructors who are disabled has proven highly effective.

Conversely, dentistry must also increasingly reach out to other disciplines. Thus, our dental faculty has provided dental information in several interdisciplinary courses on care of special populations through the School of Nursing and the School of Medicine. An interdisciplinary curriculum should include not only didactic instruction but also opportunities for clinical observation and interaction between disciplines. By building a strong foundation in interdisciplinary care, optimum benefits can be offered to the consumer with a disability.

Dentistry clearly has an integral role to play in most aspects of rehabilitation, including training and education, community outreach, and clinical services. In fulfilling this mission, dentistry makes an essential contribution to the quality of life for people who are disabled. 

### Acknowledgment

The authors wish to express their deep appreciation to the Rehabilitation Services Administration for its past and present support of programs in rehabilitation dentistry.

### Resources

1) Academy of Dentistry for the Handicapped; Executive Director: Dr. Paul Van Ostenberg; 211 East Chicago Avenue, Chicago, IL 60611. Telephone: (312) 440-2660.

2) Dental Education in Care of the Disabled (DECOD); Director: Dr. Doris J. Stiefel; School of Dentistry, SC-63,

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*The importance of educating dental professionals in the management of people with disabilities has been clearly recognized.*

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vent of tooth implants to replace missing teeth may offer viable treatment options for patients with disability who must have nonremovable dental prostheses. The adaptation of these materials and procedures to meet the complex oral conditions associated with some disabilities requires further research.

### Professional Training

The importance of educating dental professionals in the management of people with disabilities has been clearly recognized. By increasing the scope of practitioner knowledge, clinical competence and confidence, access to dental services and the quality of care for the disabled will improve. The American Association of Dental Schools has published curriculum guidelines for teaching dentistry for patients with disabling conditions (Casamassimo, Henson, Posnick, et al., 1985). However, the scope of such teaching programs at the predoctoral level varies widely, with didactic teaching hours ranging from 2-56 hours and clinical teaching from 0-144 hours (Wright & Friedman, 1987).

courses, and long-term training of 6 months and longer for the dental professional who wishes to dedicate his or her career to special patient care. Support from the Rehabilitation Services Administration helped to establish experimental and innovative training projects in dentistry. Categorical funding for training in rehabilitation dentistry is essential to maintain such programs in the future.

In view of the interdependence of dentistry and other disciplines in rehabilitation services, each discipline must become more familiar with the basic principles and goals of the other professions, and all must be sensitized to the needs of the consumer who is disabled. Such knowledge and awareness are best acquired through inclusion of an interdisciplinary core component in the curriculum of each of the rehabilitation disciplines. This approach has been tested and found highly valuable (Stiefel & Truelove, 1985; Holtzman, Bomberg, Berkey, et al., 1988). For example, numerous disciplines participate in the teaching of the DECOD courses at the University of Washington:



# Mutual Help Groups and the Rehabilitation Process

Gary E. Holmes, M.L.S., M.S.

Ronald H. Karst, Ph.D.

Lloyd R. Goodwin, Jr., Ph.D., C.R.C.

*Although mutual help groups remain outside the official services of public rehabilitation agencies, they offer people with disabilities many benefits and opportunities, and can enhance the rehabilitation process when employed with other services. This article examines some of the benefits people with disabilities gain through active participation in such groups and explores some of the ways in which the rehabilitation professional can work with mutual help groups on behalf of the individual client. The main theme of the article is that mutual help groups constitute a valuable community resource which can play an important role in the lives of people with disabilities while augmenting any formal services provided by public agencies.*

## Mutual Help Groups Defined

Mutual help groups can be defined as community-based, consumer-driven social organizations whose primary focus is on collective action to improve the lives of members and others with specific disabilities and needs. Beyond this definition, however, lies the hopes and aspirations of all those with disabilities who participate in mutual help groups as a way of practicing active self-determination in the course of their own lives. The act of participating gives members a way to better understand disability and to take a personal interest in the future.

The collective action of mutual help groups often constitutes a political base whose purpose is to educate and influence the community, including rehabilitation agencies, about the needs of group members. Some rehabilitation professionals tend to avoid such groups because they are uncertain about the intent or the "target" of such political power. However, the professional who recognizes this power as a natural ex-

pression of disability rights can establish valuable relationships with such groups. Groups look upon rehabilitation professionals as assets to help members, not as "targets" for political action. Because group members and professionals share many common goals, these relationships benefit individual rehabilitation clients by enhancing the rehabilitation process within the community.

## Benefits to the Client

Mutual help groups offer the person with a disability a variety of benefits and assistance. Chief among these is social support among people with similar situations and aspirations. The mutual help group as a personal support system gives the individual a safe arena in which to explore options and goals, and to come to terms with many of the psychosocial implications of disability. Groups provide a sense of belonging that helps reduce social isolation that can arise from disability. Participation also translates into helping others with similar conditions and needs. Partici-

pation is a consumer-driven form of "barter economy" in which members help others in exchange for help for themselves (Vash, 1981, pp. 208-209).

A typical group operates like any other social organization with a special interest. Groups generally elect officers to manage the logistical needs and to supervise group planning. Mutual help groups usually include activities such as the following in the plan for a scheduled meeting:

- welcoming members, new members and visitors;
- guest speaker or educational session;
- socialization period;
- planning future activities; and
- handling any special problems presented by members.

Such activities can enhance an individual's sense of self-worth by providing a direct method whereby he or she can contribute to society and to the welfare of others. To belong to such a group can signify that the person with a disability is involved in life. Such involvement reflects a level of social interest which can serve to reduce the stress related to disability by giving the individual the opportunity to utilize exist-

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ing social skills. Recent research in social interest suggest it may be closely linked to overall good health (Zarski, Bubenzer & West, 1986). Additionally, the member contributes by helping the group carry out its collective goals.

Because the member's family may also participate in the group, existing natural support systems can be strengthened in the process. Over time, belonging to a mutual help group can assist the individual in the process of self-assessment. He or she can identify and clarify realistic needs, strengths and rehabilitation goals through interaction with other members who provide information about disability. Accordingly, groups provide a forum in which people can discuss their own progress toward specific goals during the rehabilitation process.

**T**he experience of belonging to a mutual help group can lead to member empowerment by giving each person an active voice in dealing with disability. Active participation can help preclude social withdrawal and dependency and can encourage a greater sense of personal responsibility. In essence, the mutual help group constitutes a community for its members that is geared toward their needs, but which is also an integral, functioning part of the community at large. Inasmuch as rehabilitation takes place within the community, group participation is itself a form of rehabilitation. Although membership can have therapeutic value for the individual, groups usually have other goals as well. The sharing and mutual support generated among members puts each member in a position to give help as much as to receive it, thus providing a learning experience through give-and-take.

For example, a woman who lives in a small town in Kansas joined a women's mutual help group when she faced both a divorce and a disabling medical condition. She said that she received from other members strong support, suggestions for alternatives and non-judgmental acceptance. In summarizing her experiences with the

group, she said, "My friends were too emotionally involved to give me realistic feedback. The group emphasized confidentiality, so I was able to be open with them."

Group membership, then, is not so much a matter of casual affiliation as it is a matter of belonging. This belonging may represent a way of life from which

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*For the individual member the group becomes yet another resource within the rehabilitation community through which one can gain access to new opportunities.*

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the individual derives coping experience, a sense of responsibility to others, the capacity to envision personal change, and a feeling for the continuity of life. All these experiences and values can help an individual get the most from the rehabilitation process.

Participation in a mutual help group is often a growth experience in itself. The individual joins with others to share information and experiences about disability and about life with disability. He or she can learn how others have dealt with the day-to-day demands of normal living and how others have handled unique or situation-specific challenges. In our society there are few opportunities and occasions that provide a setting in which people can relax and tell their stories.

Perhaps most important, the individual can learn how others have managed to maintain or construct interpersonal relationships. Mutual help stems mostly from mutual support and education. Such support places the group in the position of functioning as an extended family. Even though the individual's actual family may participate in the group, the extended family nature of the group bolsters other existing support. The member's actual family also receives this support. This augmentation is particularly important when an individual experiences a setback in dealing with the world. Disability can have just as much impact on the family as it can on the individual with a disability.

So the mutual help group makes a place for everyone, a place in which family relationships can be strengthened through better understanding.

As an extended family, a mutual help group can add new dimensions to the client's life. A man in Topeka, KS, who for several years has attended a support group for professional people with al-

cohol-related problems, explained that the personal importance of group participation may remain even after an initial problem has been resolved. "I no longer attend for any therapeutic value related to my past drinking. Now I attend to help others who could not make it unless we continue providing support and encouragement," he said.

### Political Issues

Mutual help groups are often organized to improve members' welfare through direct political action. This characteristic, however, should be welcomed and respected by rehabilitation professionals. It forms the basis for self-advocacy and self-determination, two concepts that traditionally have given meaning and power to the rehabilitation process. As a politically oriented organization, a mutual help group typically arises as a grassroots movement to improve the quality of life for people with a specific disability. For the individual member the group becomes yet another resource within the rehabilitation community through which one can gain access to new opportunities.

**P**olitical power of a group grows out of the collective strengths and goals of the members. Typically, a group seeks first to educate its own members about their rights and obligations by exploring laws and policies pertaining to services and opportunities in the public sector. So a primary task of



the group is to understand the services, programs and goals of public agencies that have roles in rehabilitation and client welfare. The political agenda of the group becomes a matter of helping one another obtain available services in accordance with the intent of public laws and policies.

This political agenda is based on the notion that public agencies are accountable to those they serve. In general, a group's interests are not so much different from those of a public agency, unless of course the group perceives that an agency is not living up to its mission. Such a view is consistent with the ethics of rehabilitation professionals and of public agencies that strive to fulfill their respective missions. In this sense a mutual help group shares common values with public programs and agencies throughout the rehabilitation community. The political interests of a group are usually well-intentioned. Mutual help groups generally recognize that public agencies have finite resources and specific missions which cannot be altered except through formal changes in public law or policy. Groups can and do put their political clout to use when they perceive that members are not receiving from an agency those services for which they are eligible. Again, this is an expression of consumer awareness and self-determination. Such awareness can have a positive impact on the relationship between a group and the rehabilitation professional who serves the members. The client and the professional may have a similar knowledge about client needs and the rehabilitation process itself.

The client who possesses a clear understanding of the rehabilitation process, the agency's mission and available services can enhance the rehabilitation process by arriving at a meeting with the professional with specific and realistic goals to discuss. In turn, this can help the professional move more quickly through assessment and planning phases so that rehabilitation services can be allocated that much sooner for the client's benefit. For example, a

vocational rehabilitation counselor who encounters such a client may find that the client has already given much thought to an appropriate vocational objective and to how that objective can be reached. Such a client can be highly motivated and well-informed. An attitude of optimistic self-determination may characterize the client's first contact with the rehabilitation professional. This psychological posture can give rise to improved self-worth, a sense of active responsibility for one's own rehabilitation and a willingness to enter into the rehabilitation process as an equal, cooperative partner.

A rehabilitation professional welcomes such attitudes as important contributors to rehabilitation outcomes. In this way, the mutual help group can help a client develop the wherewithal to seek a better life through planned, intentional change. Much of the political effectiveness of mutual help groups stems from their concerted effort to keep group members informed about pertinent disability research, programs and laws. The well-informed member makes a well-informed rehabilitation client, one who can have high expectations of rehabilitation professionals. These expectations, as well, signify that the client is from the start an active participant in his or her own rehabilitation.

Many resident rehabilitation programs now allocate time for client-driven mutual help groups to meet during resident phases of client training. For example, the Kansas Rehabilitation Center for the Blind in Topeka encourages informal meetings so clients have the opportunity to share experiences with one another. The administrator of that facility said such groups are particularly valuable and effective because the clients have different degrees of vision loss and thus experience disability in different ways. As the administrator put it, "Sometimes the informal sharing of experience serves as the catalyst which leads to adjustment and acceptance by the clients." She added that this sharing often is more meaningful to the client than the more formal reha-

bilitation counseling process. Thus clients help one another understand the loss of vision as a life adjustment issue, not merely as a disability.

The rehabilitation professional who serves such a client can find both challenge and opportunity. While it may be a challenge to live up to the client's expectations regarding quality of services, the professional also has an opportunity to help a client realize his or her full potential. The client and the professional share a common value of making the rehabilitation process as meaningful as possible.

### **Mutual Help Groups as a Rehabilitation Resource**

Any community group which provides help to people with disabilities can be considered a rehabilitation resource. Mutual help groups, however, are special in several ways. Because they are consumer organizations operating outside the agency arena, they are neither owned nor controlled by rehabilitation agencies. Mutual help groups have as much to offer the professional as the professional has to offer the groups. The rehabilitation professional who has a genuine desire to help such groups and to work with them on the behalf of clients will generally find them receptive. Accordingly, the professional can consider the groups as natural community resources for rehabilitation clients in the future and should treat such groups with respect and professional courtesy.

Mutual help groups typically provide members with a variety of services aimed at helping them achieve specific goals. Specific services can include transportation, employment information and education, disability education and service information, family and individual social support, daily living skills training, peer counseling, community exploration, personal advice, planned entertainment, self-advocacy training, help with problem resolution, and housing and financial information.



A member who is also a rehabilitation client can thus make use of these services to enhance his or her own rehabilitation plan; and when these services are used *instead* of agency services, the agency may show a "net gain," since its own similar services can be used to help other clients.

This is not meant to suggest that an agency uses a mutual help group's resources to preserve its own or merely because they are available. Any services the group offers are allocated according to member needs and desires. The client receiving help from the group responds by helping other members. In this way the service or help is more akin to normal community interaction in which friends help friends. This quality leads to consumer empowerment—people helping themselves toward self-determination.

**T**he rehabilitation professional can honor this spirit of empowerment by asking the client to explore any help available through the group. While this help is taken into account as a resource when the client and the professional plan the rehabilitation process on an individualized basis, an agency can provide any other services the client needs to achieve identified rehabilitation goals.

The professional can also serve as a guest speaker at meetings where he or she can help clarify information a group might have about policies and services. Thus the professional can learn about any special problems the members may have and can display a willingness to assist the group in any appropriate way.

While mutual help groups operate on a voluntary basis according to the interests and abilities of the individual members, most derive a certain stability from being consumer-driven. An important feature is that services and support provided to members can continue long after professional rehabilitation services are completed. Groups continually attract new members who help provide continuity of support, as givers as well as recipients of support. Mutual help groups stress a common identity through a shared life situation

more than other groups (Corey & Corey, 1987, p. 13).

### **The Rehabilitation Professional and Mutual Help Groups**

Rehabilitation professionals should identify the following characteristics of mutual help groups in his or her community:

- Which groups are active in the community and which disability groups do they represent?
- What educational and service programs does each group provide to its members?
- Are family members invited to participate in the groups?
- Have groups offered support in the past to help members during and after the period in which rehabilitation services were provided by agencies?
- What can the rehabilitation professional do to help the group provide support to its members?

It is not usually difficult for a rehabilitation professional to learn about mutual help groups in the community. In many urban areas directories of groups are published and updated regularly, while in smaller communities the rehabilitation professional can discover such groups through day-to-day contacts. The rehabilitation professional who works with people who have different kinds of disabilities may find that a good working relationship can be formed with a few prominent groups that address the needs of the majority of clients. Other groups can be contacted on an "as needed" basis for clients who have less common disabilities.

In some instances participation in a mutual help group may be included as a needed service in rehabilitation planning. For example, group participation is often incorporated into "treatment" plans for people with disabilities, such as alcohol and drug abuse disorders, and becomes a routine part of many aftercare programs (Seligman, 1990, p. 172). Such treatment remains consumer-driven even when group involvement is identified as a needed service. It is im-

portant that the rehabilitation professional remember that his or her relationship with any mutual help group is a give-and-take proposition, and that even when specific clients are not involved professionals can help groups in a variety of ways. Since most groups welcome professionals who are willing to explain agency programs and policies at meetings, this serves an educational function to prepare members should they later become rehabilitation clients.

Once the professional establishes a sound working relationship with a mutual help group, the group may serve as a referral source; the group can refer members in need of rehabilitation services and the professional can refer to the group those clients wanting to participate. This exchange is aimed at the same common goal of helping people with disabilities improve their lives. Such a relationship reflects the fact that the client, the professional, the agency, and the mutual help group all belong to the same rehabilitation community in which the client's needs can be voiced.

Because client confidentiality as provided by law must still be respected, the rehabilitation professional can only refer clients to mutual help groups with the clients' permission. Additionally, the professional cannot discuss one client's rehabilitation with other group members unless specifically requested to by the client. Conversely, clients referred to the rehabilitation professional by mutual help groups enjoy the same right to privacy.

**O**n a policy level, mutual help groups can provide public agencies with unique and valuable information in the form of feedback. Groups can help to inform agencies of the changing needs of specific disability groups and can serve as critics of the policies and programs offered by rehabilitation agencies. It is important that the individual rehabilitation professional working with mutual help groups be sensitive and receptive to such feedback.

*Continued on page 33*



# NEWS, NOTES, ANNOUNCEMENTS

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## Voluntary Health Groups Spends \$2.19 Billion Combating Disability

Figures released recently by the National Health Council show that voluntary health agencies such as the Alzheimer's Association, the American Red Cross, the Epilepsy Foundation, and the National Multiple Sclerosis Society, and others spent a record \$2.19 billion to combat disease and disability in 1988, the latest year for which such uniform audited data are available.

The 34 reporting agencies, all members of the private, standard-setting National Health Council, spent \$742 million on community services, \$437 million on public education, \$347 million on patient services, \$215 million on research, and \$72 million on professional education. These program services accounted for 82.5 percent of the agencies' total expenses, a figure consistent with the Council's standards requiring high program outlays. Management costs were kept to 7.8 percent of total expenses, while fund raising accounted for 9.7 percent of overall expenses.

The Council has strengthened its longstanding annual review and standards enforcement processes to enhance public confidence in these health agencies, especially since some 57.8 percent of total revenues come from public contributions.

## Ohio Unit Safeguards Handicap Parking



*Deputy Anthony Izzi issues a traffic citation for vehicle parked in handicap parking area at the Saybrook Plaza in Ashtabula, Ohio. Ashtabula County Sheriff William K. Johnston (right) instituted the Handicap Parking Enforcement Unit, which consists of disabled volunteers.*

Ashtabula County (Ohio) commissioners recently approved the creation of a county handicap parking enforcement unit, comprised of people with disabilities and authorized to ticket people parked illegally in handicap parking spaces.

Sheriff William K. Johnston said state law provides for the creation and operation of the handicap parking enforcement unit.

Anyone who parks illegally in a handicap parking location can be tick-

eted by members of the special unit. Tony Izzi, who was instrumental in having the law enacted, said that even someone with a disability can be ticketed if that person parks in a handicap parking space and remains in the vehicle while a passenger without a disability gets out to patronize a business.

The sheriff's department is preparing a training program for the unit, which at first will consist of 10 people. Parking illegally in a handicap parking space carries a minimum fine of \$25 in Ohio.



## Study Shows Exercise Beneficial for Children Who Have Arthritis

Children with arthritis can increase their physical fitness at the same rate as children without arthritis through vigorous exercises without damage to affected joints, according to new data presented recently in Seattle at the National Scientific Meeting of the Arthritis Health Professions Association, a section of the Arthritis Foundation.

Although aerobic exercise previously has been proven beneficial for adults with arthritis, little evidence was available about the affects of aerobic exercise on children with arthritis. Consequently, healthcare professionals have been very protective of children and what they can or cannot do with their joints.

"Although more studies are needed in this area, this study indicates that we can be more vigorous with children who have arthritis and encourage them to be more physically active with such activities as bicycling, swimming, walking, and others," said Carolee Moncur, P.T., Ph.D., the author of the study that was conducted at the University of Utah.

The study involved comparisons between children with and without arthritis with an average age of 13 years. The children participated in a 12-week conditioning program by riding a stationary bicycle three times per week. Although the overall physical condition of the children with arthritis was not as good as the other children at the beginning of the study, their physical fitness increased at the same rate as those without the disease during the conditioning. The mean joint count where pain was noted decreased from 25 to 20 joints, and no significant problems occurred as a result of the activity.

## Physicians, Patients Differ on Effective Arthritis Treatment

A survey of physicians and patients has revealed a substantial difference in opinion that may limit the effectiveness of arthritis treatment.

The differing views include how well people with arthritis follow a doctor's instructions, the usefulness of various treatments and the best ways to educate patients about their health, according to new data presented recently in Seattle at the National Scientific Meeting of the Arthritis Health Professions Association, a section of the Arthritis Foundation.

The survey indicates that physicians believe people with arthritis follow prescribed action about medication, exercise and education. However, 15 percent of people taking medications, 25 percent of people using splints or braces, and just over 11 percent of people prescribed range-of-motion exercise report that they never followed the treatment as prescribed. Another 9 percent of the patients report never having followed a diet even though it was prescribed.

The physicians and patients also differed in their beliefs about the relative benefits of various treatment options for arthritis. While physicians did not view medication as harmful, 11 percent of patients believed medication used to treat arthritis could be harmful.

Physicians thought the best ways for their patients to learn more about their condition was through the physician (82 percent), newsletters (40 percent) and an education day (40 percent). In contrast, people with arthritis reported that they want to receive information about their condition through newsletters (79 percent), radio/television (75 percent) and self-help programs or materials (73 percent). Physicians as a source of education were listed fourth (66 percent) by patients.

The implications of the study shows that a difference in beliefs exists between physicians and their patients that could interfere with effective treatment. Patients are likely to assess the possible risks and benefits of various treatments quite differently than physicians would. Physicians are likely to overestimate how often their patients comply with instructions. Consequently, better communication should be established and education about the disease should be communicated through additional channels than those now viewed as best by the physicians, according to John P. Allegrante, Ph.D., a professor at Teachers College of Columbia University, an arthritis education researcher in the Cornell Multipurpose Arthritis Center at the Hospital for Special Surgery and the person who conducted the study.

The survey involved 100 patients and 68 rheumatologists and orthopedic physicians at the Hospital for Special Surgery, a major referral center for arthritis and musculoskeletal diseases. Dr. Allegrante cautioned that the study should be interpreted carefully because the patients interviewed were not necessarily those of the physicians interviewed. The study was presented at a scientific meeting of the Arthritis Health Professions Association (AHPA), the health professional section of the Arthritis Foundation. AHPA is comprised of nurses, occupational and physical therapists, physicians, and others interested in arthritis care.

The Arthritis Foundation is the source of help and hope for an estimated 37 million Americans who have arthritis. The Foundation supports research to find the cure for and prevention of arthritis and seeks to improve the quality of life for those affected by arthritis.



# Champion of Disability Rights Honored with \$50,000 Prize

A \$50,000 prize has been awarded to Judith Heumann for significantly improving the quality of life for people with physical disabilities. Ms. Heumann, who had polio as a child and uses an electric wheelchair, is the co-founder of the World Institute on Disability in Oakland, CA. She was selected as the winner of the first Henry B. Betts Award by a blue ribbon jury that included leaders such as Robert W. Galvin, Senator Robert Dole, Fay Vincent, the Reverend Theodore M. Hesburgh, and Michael DeBakey, M.D.

The award was established by the Prince Charitable Trusts and is named for rehabilitation medicine pioneer Henry B. Betts, M.D. Dr. Betts, medical director and chief executive officer of the world renowned Rehabilitation Institute of Chicago (RIC), is an internationally recognized expert and respected spokesperson for the rights of people with disabilities.

Ms. Heumann, selected from more than 100 nominations resulting from a nationwide search, received her award during a ceremony at the Library of Congress.

"Like many people with disabilities, Judy looked around and saw that to contribute to society as she knew she could, she would have to change the world," commented jury member Senator Robert Dole, long-time activist for people with disabilities. "What makes Judy remarkable is that she did," he continued.

After filing a lawsuit against the City of New York for her right as a qualified educator to teach in the public schools, Heumann was hired as the city's first teacher with physical disabilities. In 1973, she joined the Center for Independent Living in Berkeley, CA, and was part of the group which established the principles for the disenfranchised from society—people with disabilities, children, the poor, and the elderly. Ms. Heumann has been actively involved in the fight to gain personal assistance services for Americans of all ages who



*After being awarded the first annual Henry B. Betts Award, Judith Heumann poses outside the U.S. Capitol with Frederick H. Prince (left) and Dr. Henry B. Betts.*

have disabilities. Further, she is one of the few leaders to encourage funding for disability organizations in developing countries.

"Judy helps shape public policy and perception—she paints with a broad brush and improves the world for all of us. There are countless others who work outside of the spotlight. And they too are winning today, because it is our hope that they see this award as a herald of the changing times," said Henry B. Betts, M.D.

"I'm honored to be the first winner of the Henry B. Betts Award. One of the reasons I have so admired Dr. Betts is because he was among the first professionals to recognize the importance of the independent living movement," said Ms. Heumann. "Dr. Betts knows that disability isn't a tragedy. The

tragedy is being excluded from contributing to society because of a narrow doorway, or lack of a diploma or job. He has shown society that its narrow way of thinking must change in order to benefit from the millions of Americans with disabilities. Selecting me, a disabled woman, for the first winner points out the important role disabled people have been playing in our fight for equality," she added.

Fay Vincent, commissioner of baseball and Henry B. Betts Award jury member, said, "Judy's accomplishments are an inspiration for people with disabilities — and she is a role model for all Americans."

"We created this annual award to be a kind of mirror. So that when people — nondisabled or with disabilities — look at the winner, they will see reflected there the potential in themselves. Releasing potential is the essence of rehabilitation medicine, in good measure, thanks to Henry Betts. And Judy's work embodies the spirit of the Henry B. Betts Award," said Frederick H. Prince, trustee of the Prince Charitable Trusts.

The Prince Charitable Trusts was established by Frederick Henry Prince to support a variety of philanthropic causes.

RIC was the first comprehensive rehabilitation hospital designed to combine professional education, research and patient care. One of the leading facilities of its kind, RIC's reputation attracts patients and government leaders from around the world. Among those who have taken notes from Dr. Betts on how to replicate the environment at RIC are Jihan Sadat, wife of the late Anwar Sadat, and Deng Pu Fang, a major force behind the rehabilitation center in Beijing and the paraplegic son of China's Chairman Deng Xiao-Ping. RIC is heralded for excellent patient care closer to home, as well, and in 1990 the Institute was named one of the top 10 rehabilitation hospitals in the country by *U.S. News & World Report*.



## New Sign Language Publication Offered

A new book on the linguistics of sign language, edited by an associate professor in the Department of Communication Research at the National Technical Institute for the Deaf (NTID), a college of Rochester Institute of Technology (RIT), in Rochester, NY, was published recently by the University of Chicago Press.

*Theoretical issues in Sign Language Research, Volume 1: Linguistics*, is a compilation of 14 separate articles, written by linguistics experts, that focus on the phonology, morphology, syntax, and semantics of sign language. Dr. Susan Fischer of NTID edited the book with Dr. Patricia Siple, associate professor of psychology and director of the linguistics program at Wayne State University in Detroit.

According to Fischer, the book in-

cludes perspectives on six sign languages—American, Swedish, New Zealand, Taiwanese, Chinese, and Brazilian Cities and provides an opportunity to see the linguistic similarities and differences between different sign languages. The authors present some interesting new ways of analyzing the most basic kinds of structures above and below the level of the “sign.”

The 338-page publication is targeted to linguistics professionals and will primarily be marketed to colleges and universities.

The book is an outgrowth of a conference held in Rochester, NY, in 1986, jointly sponsored by NTID and the University of Rochester, titled “Theoretical Issues in Sign Language Research.” This first volume, which focuses on the linguistic structures of sign language,

will be followed by publication of a second volume, *Theoretical Issues in Sign Language Research, Volume 2: Psychology*, which will present perspectives on the psychology and acquisition of sign language.

NTID, one of nine colleges of RIT, is the world’s largest technological college for deaf students. Created by Congress and funded primarily by the U.S. Department of Education, NTID represents the world’s first effort to educate large numbers of deaf students within a college campus planned primarily for hearing students. Nearly 1,100 of RIT’s 13,000 full- and part-time students are deaf. Ninety-five percent of NTID’s graduates obtain jobs related to their programs of study.

In addition to the academic programs based at NTID, RIT’s deaf students also benefit from nearly 200 other technical and professional courses of study offered by RIT’s other eight colleges.

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## Exercise Beneficial to Arthritis Patients, Latest Studies Show

Although once believed to cause undue stress and strain on joints, physicians are now finding that exercise among people with arthritis is not as detrimental as previously believed. Consequently, medical doctors are now prescribing specific exercises to help people with arthritis maintain joint motion. Physicians also are encouraging participation in recreational exercise to increase overall emotional and physical health, according to the Arthritis Foundation.

A newly released *Bulletin on the Rheumatic Diseases*, distributed by the Arthritis Foundation to physicians nationwide, states that emerging research in the area of exercise and arthritis has provided knowledge about what specific kinds of exercise should be prescribed by physicians for certain types of arthritis, as well as the benefits of general recreational exercise among

people with the disease.

According to the bulletin, an appropriate and well-supervised exercise program for people with arthritis can help increase their strength and improve joint function. However, it also encourages health professionals to monitor the prescribed program to assure that joints are minimally stressed and that the exercise produces no undue fatigue. Isometric exercise is the preferred form, with low weight and low repetition exercises added when joints are no longer painful or swollen.

“In addition to the prescribed exercise, endurance training through recreational exercise can make daily activities, work and social interactions easier,” said Arthur Grayzel, M.D., the Arthritis Foundation’s senior vice president for medical affairs.

“We now know that one of the worst

things to do when you have arthritis is to become inactive. You must continue using the involved joints to the extent possible and talk to a physician about ways to maintain range of motion,” Dr. Grayzel said.

“A good, general rule of thumb is that you should cut back exercise, or any activity, if you experience fatigue or pain for more than one hour after stopping the exercise.”

For more information about exercise and arthritis, call the Arthritis Foundation Information Line toll free at (800) 283-7800. The Arthritis Foundation is the source of help and hope for an estimated 37 million Americans who have arthritis. The Foundation supports research to find the cure for and prevention of arthritis and seeks to improve the quality of life for those affected by arthritis.



## ADA Certification Offered at Conference

The ADAptive Works Exposition and Conference at San Francisco's Moscone Convention Center, June 6-8, promises to present the most comprehensive ADA Consultant Certification Program in the United States. This certification program was designed exclusively for health care dealers as a result of the passage of the Americans With Disabilities Act (ADA).

The ADA Consultant Certification Program will give health care dealers the tools and knowledge to help community businesses nationwide come into compliance with the act. In addition to employment opportunities, the legislation also applies to accessibility in government buildings, public accommodations, transportation and telecommunications.

"The health care dealer stands to benefit not only from business compliance, but also from the residual effects of this new law. Since more disabled persons are expected to be entering the workplace, they will have the discretionary incomes to buy better health care products for themselves," said Ted Conrad, president of SEMCO, show producer. "With ADA affecting so many areas, a need exists whereby health care dealers have the means to take full advantage of the opportunities created by ADA. Our certification program fulfills that need."

A variety of rehabilitation professionals from both government and private sectors will participate in this ADA education program to discuss problems with and solutions to ADA compliance. A series of 1-hour programs will give health care dealers a complete, informative package on how to help businesses implement ADA.

Four main topics will comprise the agenda: reviewing the regulations of the act; using established dealer product skills in helping businesses to comply; utilizing other resources; and marketing ADA related services to let

businesses know the dealer is their ADA authority.

Understanding the concept and intent of the legislation will receive priority attention. The law prohibits discrimination against individuals with disabilities in public and private sector businesses and seeks to ensure that those individuals have access to transportation and public accommodations. Telecommunication services must also be made available to people with speech and/or hearing impairments.

How the existing health care dealership and its people can use their skills to help businesses meet ADA requirements will receive major emphasis. Most employers do not understand that a simple ramp can bring them within ADA guidelines. Nor do they realize that making a building or work area usable by disabled persons often costs less than \$500.

Dealers will also receive full knowledge of the resources available to them and their communities. While the accommodations of installing a wheelchair ramp are quite obvious, others are not. For example, what if a qualified applicant for a computer operator position is blind? What if an applicant for a telephone-related job is hearing impaired? Fortunately, help is available through the ADA Consultant Certification Program.

Upon completion of the program, dealers will receive the ADA Certification Kit that will assist them in making their community aware of their service. The kits include press releases and ads to announce their certification and qualification as an ADA consultant. Easy-to-understand summaries of the ADA legislation as well as sample speeches to present to local civic groups will enable dealers to become their communities' source for ADA compliance.

The ADA Consultant Certification Program will only be offered at the ADAptive Works Exposition & Conference in San Francisco. For more information contact Marjorie D. Price at (404) 998-9800, FAX: (404) 642-4715.

## Rehabilitation Medicine Conference Scheduled

The Joint Annual Meeting of the American Congress of Rehabilitation Medicine (ACRM) and the American Academy of Physical Medicine and Rehabilitation (AAPM&R) will be held October 27 to November 1, 1991, at the Sheraton Washington Hotel in Washington, DC. The theme for this year's meeting will be "Education in Rehabilitation: Our Heritage. Our Future."

For further information contact Michael Weinberg, Manager of Publications, ACRM/AAPM&R, 122 South Michigan Avenue, Suite 1300, Chicago, IL 60603-6107. Telephone: (312) 922-9366/68. FAX: (312) 922-6754.

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# NEW PUBLICATIONS AND FILMS

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## **Key Issues in Mental Retardation Research.**

*Proceedings of the Eighth Congress of the International Association for the Scientific Study of Mental Deficiency. Edited by William I. Fraser. Technical editor, Charles G.I. Russell. Routledge, Chapman & Hall, 29 West 35th Street, New York, NY 10001. 506 pages. Hardcover, \$79.95 (U.S.), \$95.95 (Canada).*

This is a selection of representative papers from the proceedings of the Eighth Congress held August 21–25, 1988, in Dublin, Ireland. In all, some 160 papers were presented. Each of the papers selected illustrates a key issue, including the effects of dietary patterns on the developing brain, the impact of new technologies, consumer choice, and the problems of aging.

## **Since Owen. A Parent-to-Parent Guide for Care of the Disabled Child.**

*Charles R. Callanan. The Johns Hopkins University Press, 701 West 40th Street, Suite 275, Baltimore, MD 21211. 466 pages. Hardcover, \$39.95; softcover, \$16.95.*

A 30-year struggle to cope and an ongoing search for answers to his son's multiple disabilities—which remain undiagnosed—form the groundwork of the author's book. An educator and father of six children, Callanan draws on his extensive experience of life "since Owen" in this resource for other often-overwhelmed parents of disabled children. He identifies the issues, points out where to turn and how to move through mazes (hospitals, agencies and services, for starters), how to live with oneself and others, and how to create

opportunity through action. He spells out the procedures of pursuing every child's legal right to an appropriate education, as well as for constantly developing independence in the disabled child who will one day move out of the education system into the adult world.

## **Health and Lifestyles.**

*Mildred Blaxter. Routledge, Chapman & Hall, 29 West 35th Street, New York, NY 10001. Hardcover, \$62.50 (U.S.), \$75 (Canada); softcover, \$23 (U.S.), \$27.50 (Canada).*

What fosters a healthy lifestyle? How much responsibility does the individual have for his or her own health? Which is the more significant: the social circumstances in which people live, or lifestyle habits such as exercise and smoking? This book purports to contribute important new evidence to the current debate about the health of the British population. Based on a national survey of 9,000 people which was carried out by an interdisciplinary team at the University of Cambridge Medical School, this work investigates issues such as measured fitness, declared health, psychological status, life circumstances, and health-related behavior, attitudes and beliefs.

## **Facing Physical Violence. Problems in Practice.**

*Glynis M. Breakwell. Routledge, Chapman & Hall, 29 West 35th Street, New York, NY 10001. Hardcover, \$25 (U.S.), \$30 (Canada); softcover, \$10.95 (U.S.), \$13.50 (Canada).*

The author seeks to offer guidance to people in the caring professions on how best to manage violence and avoid physical abuse by the very people they

are trying to help. She discusses what it is that may invite others to be violent, how professionals can change their behavior so they can work with the powerful emotions experienced by clients without inviting unnecessary risk and how to defuse actual encounters which are turning nasty.

## **Aging and Health Care.**

*Social science and policy perspectives. Edited by Marcia G. Ory and Kathleen Bond. Routledge, Chapman & Hall, 29 West 35th Street, New York, NY 10001. Hardcover, \$49.95 (U.S.), \$59.95 (Canada); softcover, \$19.95 (U.S.), \$23.95 (Canada).*

This volume is edited and composed of papers written by a variety of experts and strives to bring some of the best social and behavioral research to bear on how the problem of health care for older people must be defined so that meaningful solutions may be found. It focuses on social science research of two dynamic trends that are receiving widespread recognition—the aging of the U.S. population and its increasing need for health care services.

## **Pediatric Rehabilitation.**

### **A Team Approach for Therapists.**

*Martha K. Logigian and Judith D. Ward, editors. Little, Brown and Company, 200 West Street, Waltham, MA 02254. 340 pages. Hardcover, \$42.50, plus \$1.50 postage and handling.*

This book, which presents programs for children with physical or emotional problems, is designed for students and entry level clinicians in allied health and special education, particularly in the dis-



ciplines of occupational therapy, physical therapy and speech-language pathology.

The text begins with an introductory chapter on normal development and descriptions of the health care team. Other chapters are devoted to the following conditions and treatment and other problems associated with them: cerebral palsy, mental retardation, infantile autism, learning disabilities, attention deficit disorders/hyperactivity, communication disorders, and juvenile rheumatoid arthritis. Also, there is an entire chapter on physical disorders, one on medical disorders and another on psychosocial disorders.

### **Subpersonalities.**

#### **The People Inside Us.**

John Rowan. Routledge, Chapman & Hall, 29 West 35th Street, New York, NY 10001. 242 pages. Softcover, \$14.95 (U.S.), \$17.95 (Canada).

Covering the phenomenon of the divided self, how part of us wants to do this, another wants to do that, the author argues that we all have a number of personalities that express themselves in different situations and that by recognizing them we can come to understand ourselves better and improve our relationships with others.

In looking at *where* subpersonalities come from, the author explores ideas from the earliest times—4000 BC—through the work of Mesmer in the 19th century up to the more recent ideas of the 1960's and the present day and adds insights gained from his own work as a consultant psychologist, a therapist and counselor. He has been studying subpersonalities and running numerous workshops on the subject for the past 20 years.

### **The Concise Dictionary of Psychology.**

David A. Statt. Routledge, Chapman & Hall, 29 West 35th Street, New York, NY 10001. 136 pages. Softcover, \$9.95 (U.S.), \$11.95 (Canada).

An easy-to-use aid for students and professionals alike, this book gives clear

and succinct definitions of psychological terms most commonly found in popular writing and introductory textbooks.

### **Enhancing Your Public Relations.**

#### **A guide for designing effective communication strategies for community-based vocational rehabilitation programs.**

Beth DePoint. Materials Development Center, University of Wisconsin-Stout, Menomonie, WI 54751. 82 pages. Softcover, \$22.50, plus \$2.50 shipping.

Written for people who are responsible for communication and public relations in organizations, this guide addresses several methods of communication to help decide which techniques are most appropriate for formulating and initiating a solid public relations program specifically designed for the agency and the programs it offers.

Chapters include: communicating with the public, developing a strategic public relations plan, developing print communication, developing audiovisual communications, and measuring success.

### **American Indian Autobiography.**

H. David Brumble III. University of California Press: 2120 Berkeley Way, Berkeley, CA 94720; and 50 E. 42nd St., R. 513, New York, NY 10017. 289 pages. Softcover, \$12.95.

This book contains a wealth of information about American Indians which should be of special interest to scholars and of general interest to people who provide social services to American Indians. The material is provided in the form of narratives compiled from a number of different sources and cultural groups—from Crows, Hidatsas, Navajos, Osages, Kiowas, Hopis, Pequods, Chippewas, Kwakiutls; from warriors, farmers, Christian converts, rebels and assimilationists, Peyotists, shamans, hunters, Sun Dancers, artists, visionaries, mothers, fathers, and English professors.

### **Normalization in Practice:**

#### **Residential care for children with a profound mental handicap.**

Edited by Andy Alaszewski and Bie Nio Ong. Routledge, Chapman & Hall, 29 West 35th Street, New York, NY 10001. 280 pages. Hardcover, \$57.50 (U.S.), \$69 (Canada).

Focussing on care within the voluntary sector and written with the child in mind, this work explores the administration, strategy and problems facing careers in a children's home. The authors discuss the problems involved in setting up and operating small community-based facilities, examine the difficulties of evaluating progressive services that are influenced by the philosophy of normalization, and highlight the lessons from which other providers of services are able to learn.

Written by experienced researchers, with contributions from experienced service managers, *Normalization in Practice* offers advice on managing innovation efficiently without neglecting the needs of the child. Detailed interviews are combined with theoretical insight to provide a guide for students and practitioners and a model for academics undertaking evaluative research.

### **Career Perspectives:**

#### **Interviews with Blind and Visually Impaired Professionals.**

Compiled by Marie Attmore. American Foundation for the Blind, 15 West 16th Street, New York, NY 10011. 86 pages. Softcover, \$11.95, plus \$3 postage and handling. Available in large print, cassette and braille editions.

Profiles 20 successful achievers who describe in their own words what it takes to pursue and attain professional success in a sighted world. From all around the country, representing a wide range of professions, including law, science, journalism, management, and medicine, these blind and visually impaired people can serve as role models for others who want to follow career paths.

The book also addresses such topics as attitudes toward blindness and blind people, braille literacy and technology.



Many of the interviewees describe the adaptive devices and alternative techniques they use to perform their jobs successfully.

**Access to Mass Transit for Blind and Visually Impaired Travelers.**

*Edited by Mark M. Uslan, Alec F. Peck, William R. Wiener, and Arlene Stern. American Foundation for the Blind, 15 West 16th Street, New York, NY 10011. 178 pages. Softcover, \$21.95, plus \$3.50 postage and handling.*

Containing firsthand information from visually impaired travelers, orientation and mobility professionals and mass transit experts, this handbook provides a unique look at the special needs of visually impaired users of mass transit and the critical role orientation and mobility practitioners play in meeting those needs.

The book offers a wealth of interesting solutions to specific problems faced by blind and visually impaired users of mass transit. For example, the drop-off from the platform edge to the tracks in subway and train stations is an area of great concern to visually impaired rail users. In his chapter entitled "Detecting the Platform Edge in Rapid Rail Systems," Ralph S. Weule, department manager, safety and investigations, Bay Area Rapid Transit (California), evaluates the effectiveness of several tactile-edge warning systems.

Comments by blind and visually impaired travelers who contributed to this publication suggest that providing clear and concise information about the layout and operation of the transit system in alternative formats and making better use of existing public address systems would greatly improve safety and accessibility. The book contains a resource list that includes sources of equipment and materials such as tactile maps and bus number identifiers.

High-tech solutions are also explored. "New technology offers many accommodations that are not costly and could be adopted by mass transit systems in the relatively near future,"

says Alec Peck, Ph.D., senior research associate, Center for the Study of Testing, Evaluation and Educational Policy, Boston College. "Two devices that are currently being tested—Auditory Pathways, which use electronically programmed loudspeakers to guide visually impaired travelers to different locations in the transit station, and Auditory Beacons, that confirm the presence of an open railcar doorway through the use of an acoustic signal—are possible systemwide innovations that could make rapid rail travel more accessible to blind and visually impaired travelers.

Other solutions include a talking bus stop system; a tactile map that contains a three-dimensional model and a series of audiotape messages, assorted tactile and electronic guiding systems; partitions on bus and rail platforms; and the use of a tactile marker to indicate exactly where one can board a bus.

**Coping with Crises.**

*Part of the series, Problems in Practice. Glenys Parry. Routledge, Chapman & Hall, 29 West 35th Street, New York, NY 10001. Hardcover, \$32.50 (U.S.), \$39 (Canada); softcover, \$14.95 (U.S.), \$17.95 (Canada).*

The author, a clinical psychologist, looks at the nature of crises, their impact upon people and at ways of understanding and helping those facing crises to survive and find continuing meaning and purpose in life. Dr. Parry illustrates how even the worst crisis can be overcome through the power of the human spirit and with the guidance and support of others.

**Transition from School to Work: New Challenges for Youth with Severe Disabilities.**

*Paul Wehman, Ph.D., M. Sherril Mood, Ed.D., Jane M. Everson, Wendy Wood, and J. Michael Barcus. Paul H. Brooks Publishing Co., P.O. Box 10624, Baltimore, MD 21285. 336 pages. Softcover, \$23.95.*

This text offers guidance in preparing for transition in the school years, initiating

careful transition program planning, and evaluating employment options and achieving successful placements.

**Research on Multiple Sclerosis, Third Editions.**

*Byron H. Waksman, M.D., Stephen C. Reingold, Ph.D., and William E. Reynolds, M.D. Demos Publications, 156 Fifth Avenue, Suite 1018, New York, NY 10010. 120 pages. Softcover, \$9.50.*

Prepared and sponsored by the Department of Research Programs of the National Multiple Sclerosis Society, this book provides a broad based overview of current research in multiple sclerosis (MS) for those with MS and others interested in this exciting and fast moving area of research. Sections discuss the nature of the disease and its diagnosis, promising areas of research and current approaches to management.

**The Art of Psychotherapy. Second Edition.**

*Anthony Storr, Routledge, Chapman & Hall, 29 West 35th Street, New York, NY 10001. Telephone: (212) 244-3336. 208 pages. Softcover, \$13.95 (U.S.), \$15.50 (Canada); hardcover, \$39.95 (U.S.), \$45 (Canada).*

Tapping into his 30 years of teaching and practicing individual psychotherapy and writing in a style free of jargon and mystique, the author presents his case that successful psychotherapy depends on developing an intensely personal patient-therapist relationship. He contends it is essential that the psychotherapist possess a capacity for empathy with a wide range of personality types and that he be more concerned about understanding patients as whole individuals than diagnosing precise kinds of neurosis.

For the author, psychotherapy today is not just a means of curing neurotic symptoms but of helping people suffering from "problems of living."

This is a book for everyone who wants to understand what actually takes place between the psychotherapist and his/her patient.



## Reshaping the Psycho-Analytic Domain.

*The Work of Melanie Klein, W.R.D. Fairbairn and D.W. Winnicott. Judith M. Hughes, author. University of California Press, 2120 Berkeley Way, Berkeley, CA 94720. Telephone: (416) 642-4662. 256 pages. Softcover, \$11.95.*

The author describes the theories and work of Melanie Klein, W.R.D. Fairbairn and D.W. Winnicott, British pioneers in the practice and theory of psychoanalysis.

## 70 Years of Hope

*(Continued from inside front cover)*

could only have been fantasy before its passage. Rehabilitation personnel became more professional. Disabled people became more knowledgeable and more independent, and the Congress became more generous. Many of us remember the 1970's as a decade when there was enough money to almost meet the demands for services.

The 1970's also brought the creation of the Independent Living programs beginning with funding only for the Title VII, Part B, centers. It was also during this decade that the research division was split away from RSA and the National Institute on Disability and Rehabilitation Research was created under Title II.

Title V was also added to the Rehabilitation Act during this period, bringing rights, opportunity and empowerment to Americans with disabilities. The positive impact of the Title V provisions meant forward movement and growth for the VR program.

In the 1980's, the entire field of disability and rehabilitation placed renewed emphasis on employment opportunities. During this time, the supported employment amendments were added to the Rehabilitation Act, and employment barriers and work disincentives became a focus of concern. Private industry became a fully

participating partner in the rehabilitation network, and integrated, competitive employment became the primary goal for people with severe disabilities.

It was in this decade, too, that the additional independent living authorities under Title VII were funded, and enhancement of the quality of life for disabled Americans became the worthy goal of numerous social programs.

Seventy years of hope, seventy years of success, a seventy-year history that could not have been written without the determination of millions of Americans with disabilities is also a history that could not have been recorded as a success without the dedication of thousands of rehabilitation professionals and support workers. It is a story that could not have survived seven decades without the caring and generosity of the U.S. Congress and the commitment of various administrations. It is a story that could never be told without the full participation of the states, facilities, communities, universities, and the private sector.

The 1990's bring even greater challenges to vocational rehabilitation programs. With new, bold civil rights for

Americans with disabilities, there will certainly be change and expansion in the service and the delivery system. Choice and empowerment will replace hope and promise as a new generation of Americans with disabilities, more enlightened, more educated and more determined, steps forward to participate in rehabilitation programs.

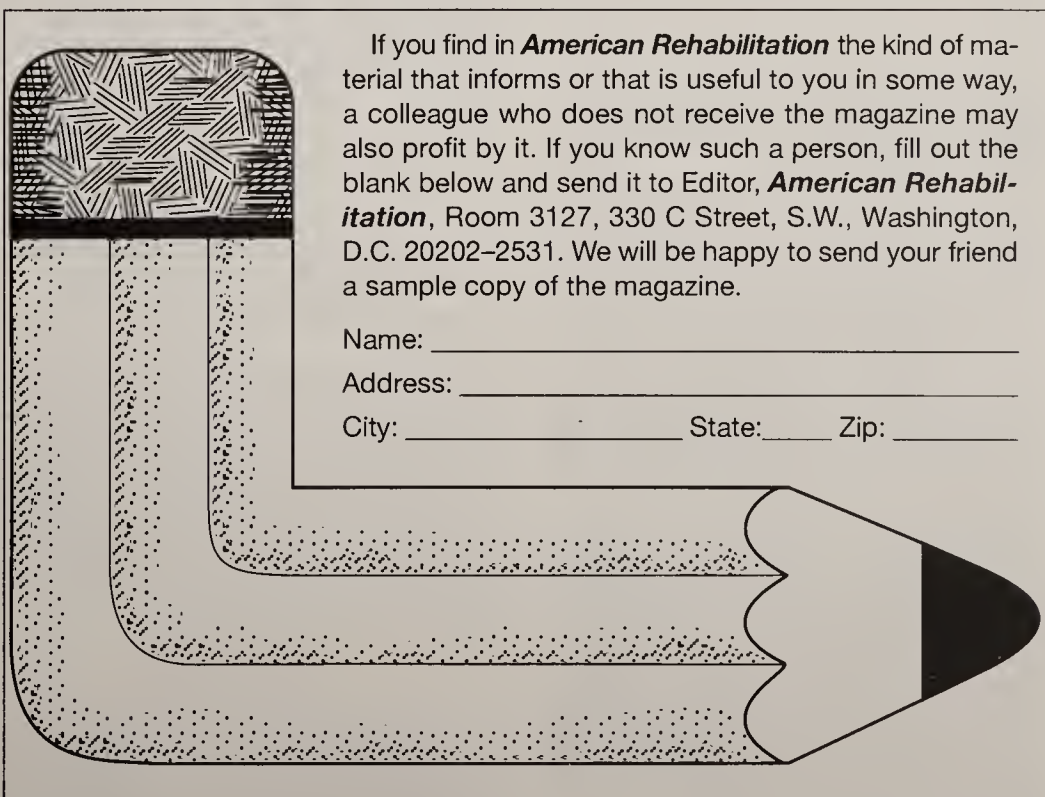
But the prevailing principles of individualization, flexibility and systematic approaches that have kept vocational rehabilitation alive and healthy for 70 years will remain unchanged. Comprehensive rehabilitation and independent living programs that lead to the pursuit and attainment of employment, independence and integration into the community will be needed just as much by new generations of disabled Americans. The foundational principles on which the program was built and has operated will live on; these will never die as long as we are a free nation made up of people who care about one another and who care about the health, welfare and future of America. There is more to be done, and we have the collective will, the knowledge and the tools to do it.

If you find in **American Rehabilitation** the kind of material that informs or that is useful to you in some way, a colleague who does not receive the magazine may also profit by it. If you know such a person, fill out the blank below and send it to Editor, **American Rehabilitation**, Room 3127, 330 C Street, S.W., Washington, D.C. 20202-2531. We will be happy to send your friend a sample copy of the magazine.

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(Continued from page 8)

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## Rehabilitation Dentistry

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### **Mutual Help Groups** (Continued from page 22)

Being open to such information means that the rehabilitation professional must respect the source, must assume that the information has merit and value, and should pass the information on to rehabilitation managers or administrators who can weigh it against other data. It is vital to the professional's relationship to a group that the group be notified when information has been given to agency managers; when this is done, group members are better able to sense that their views are being heard by the agency.


Accordingly, the group should be informed of any policy or program changes resulting from information it provided to the agency. On the other hand, if the information does not lead to changes, the group should be told the reason. Such information cannot always be acted upon immediately by an agency, since other demands, priorities and limitations can serve to postpone or nullify changes group members may think are warranted. When the group understands the reasons for such decisions, its members are more likely to understand the agency's position.

### **Conclusion**

Mutual help groups can serve as an important community resource for people with disabilities and rehabilitation professionals alike. As a social organization espousing a common goal with people who have disabilities, a mutual help group can play an important role in the rehabilitation process and in helping the individual cope with the social and personal impact of disability. Much of the popularity and success of such groups stem from the

experience of shared concerns (Seligman, 1977, p. 7), an experience which serves to focus a group's direction toward specific goals. Social involvement, self-esteem and rehabilitation aspirations can be improved through group participation.

For a group to function as a resource, the professional must recognize its legitimacy and must work to establish a meaningful relationship with its leaders and members. The political orientation of most mutual help groups must be viewed by the professional as an effective and appropriate method for people with disabilities to voice common concerns.

Mutual help groups look upon rehabilitation professionals in the community as resources in their own right. The professional who is willing to invest time and effort in building sound relationships with mutual help groups will find that they add "depth" to the rehabilitation community. Although rehabilitation professionals stand to gain from such relationships, it is the people with disabilities who stand to gain the most—better opportunities to live and work within a community in which empowerment is a reality growing out of a collaborative effort to make rehabilitation as meaningful as possible. 

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# AMERICAN Spring 1993 REHABILITATION

**Working Ideals of  
Supported  
Employment**

**Working with  
Visually Impaired  
Older American  
Indians**

**Careers in  
Rehabilitation**

**Adaptive Driver  
Training**





# SCULPTOR SOUGHT FOR SWITZER PORTRAIT BUST

The Very Special Arts Gallery and the National Rehabilitation Association with its Virginia Chapter are cooperating with the Department of Education's National Institute on Disability and Rehabilitation Research to conduct a "Call for Proposals" for original designs for The Mary E. Switzer Portrait Bust Sculpture. This sculpture will honor and memorialize Mary E. Switzer's extraordinary leadership, drive, and dedication directed to the advancement of rehabilitation legislation, research, and program services. Over several decades, her tireless efforts resulted in substantially enhanced employment opportunities and quality of life for millions of people with disabilities in the United States and worldwide.

Ms. Switzer became director of the United States Office of Rehabilitation (now known as the Rehabilitation Services Administration) in 1950, following a successful career in Federal Government. Among her many accomplishments advancing the cause of rehabilitation, Mary E. Switzer was instrumental in crafting Public Law 565 and ensuring its passage. Public Law 565 provided increased funding for research and rehabilitation education, mandated construction for new rehabilitation facilities, called for increased rehabilitation services for all Americans, and encouraged international efforts and cooperation in addressing rehabilitation issues. Throughout her life, Ms. Switzer continued to create and implement legislative and governmental initiatives on behalf of people with disabilities and their families. Her life of advocacy made a difference.



Upon completion, The Mary E. Switzer Portrait Bust Sculpture will be permanently placed in the lobby of the Switzer Building at 330 C Street, SW, Washington, DC.

The competition is open to all American artists with disabilities who are 18 years old or older. It is preferable that artists have previous experience in sculpting.

A jury of nationally recognized art experts will select a design which best reflects the life, personality, and goals of Mary E. Switzer. The jury will especially be looking for originality and demonstrations of the artist's personal style. Each artist is free to interpret and recreate the image of Mary E. Switzer according to his or her own impressions.

Artists are required to provide:

- a two-dimensional design and/or a three-dimensional model, in clay or plaster;
- a vitae or brief description of artistic experience;
- a project timeline which reflects a project completion date of October 1, 1993; and
- a budget proposal not to exceed \$20,000. This budget should include cost of materials, fabrication, and artist's fees.

Participating artists will receive a supplementary resource packet, including photography and a book about the life of Mary E. Switzer.

Artists wishing to participate should contact the Very Special Arts Gallery as soon as possible at 1331 F Street, NW, Washington, DC 20004, or telephone 1-800-933-8721 or (202) 628-0800.

# AMERICAN REHABILITATION

Volume 19, Number 1

Spring 1993

The weakest ink is better than the strongest memory.

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**People with visual impairments will have more difficulty improving their functional capacities within environments that have restricted resources. American Indian reservations are most often rural and located in remote communities with accessibility barriers and minimal services. These communities often lack professionally trained specialists to work with people who are visually impaired or blind. This article describes a program that was developed to train indigenous personnel in skills needed to aid American Indian elders who have visual impairments. The training program was a combination of workshop training, reservation-based followup inservice training and ongoing project training.**

# Training Programs for Working with Older American Indians Who Are Visually Impaired

*William E. Martin, Jr., Ed.D., CRC*  
*Keith White, Ed.D.*  
*R.C. Saravanabhavan, Ed.D.*  
*Kathy Carlise, M.A.*

The importance of the cultural/environmental context upon the behavior of people with disabilities is evident when working with people living on reservations. Lewin (1942) advanced the theoretical framework that in order to understand or to predict behavior, the person and the environment have to be considered as one constellation of interdependent factors. He called this constellation *life space*.

Marshall, Martin, Thomason, and Johnson (1991) reflect a psychology of ecology point of view when they state, "People with disabilities may have more difficulty in ameliorating their physical limitations in such environments" (p. 231). These difficulties include unemployment rates 5.47 times higher than that of the total civilian labor force (Martin & Frank, 1987), a 1.5 times higher rate of work disability than for the general population (O'Connell, 1987), and more health-related problems at younger ages than the general population (Maddux, 1987). In keeping with social affordance theory (Loveland, 1991), environments offer opportunities for perception and action to people in the context of their capacities, both physical and psychological. These perceptions and actions are in neither the environment nor person but are derived from an ecological relationship between both.

It is evident that American Indians with disabilities living on reservations have substantial unmet needs and limited resources and services. Action research methods become highly relevant under these conditions. Lewin developed a theme of social change in his notion of action research, which was an outgrowth of field theory. In explaining this concept, Lewin stated, "It is a type of action research, a comparative research on the conditions and effects of various forms of social action and research leading to social action" (Lewin, 1948, p. 203). Lewin also stressed that residents from the area being studied should actively take part in the research process. Current community-based research approaches including participatory action research (Whyte, 1991), social impact assessment (Tester & Mykes, 1981), and qualitative research (Strauss & Corbin, 1990), incorporate Lewin's thematic underpinnings. Several community-based action research projects have been conducted with tribal members to understand and improve services to Indian people with disabilities. Martin and O'Connell (1986) found that the life space factors of many individuals living on the 19 Pueblos of New Mexico consistently interfered with the interchange of effective services. An alternative service delivery approach was undertaken by the investigators to test the feasibility of a state vocational rehabilitation (VR) agency working interdependently with American Indians living on reservations to benefit from rehabilitation services. Local, indige-



nous persons living within the Pueblos were trained as rehabilitation technicians to identify individuals with disabilities in need of services and then refer them to state VR counselors. The state division of vocational rehabilitation implemented a new system of services resulting from the recommendations of the study.

Lonetree (1990) identified the service resource needs associated with delivering services within American Indian Vocational Rehabilitation Projects administered by 14 tribes throughout the nation. As a result of the study, specific training and technical assistance activities were initiated to improve service delivery. Saravanabhavan (1991) investigated the needs of the elderly American Indians who were visually impaired or blind and living on the Hualapai reservation in Arizona. He employed a triangulation method of data sources and data collection. The data sources included samples of elderly American Indians, service providers, and client records. The data collection methods included administration of the OARS Multidimensional Functional Assessment Questionnaire, an assistive device survey, and a service provider survey. A protocol also was developed to extract data from client records. From this multimethod approach, the researcher was able to make systemic recommendations to improve services. Community-based research methods used in these studies were applied to a training program to improve services to older American Indians with visual impairments.

While there have been minimal research data generated about older American Indians with visual impairments, there is some information available about the health needs of American Indian elders. Saravanabhavan and Marshall (1991) reported that American Indians "age faster" as evidenced by research that showed that American Indians experienced a lower life expectancy and quality of life when compared to non-Indian populations. Because of this phenomenon, American Indians acquire limitations in activities of daily living at earlier ages than the non-Indian population. The researchers

pointed out that "unless providers of health care and human services are reservation-based, they may not see this population" (p. 17). Edwards, Edwards, and Daines (1980) surveyed personnel from Bureau of Indian Affairs offices, tribal headquarters, and state departments of aging serving American Indian/Alaska Native elderly. They found that paraprofessional staff were most often employed to provide services to older American Indian people. They concluded that "more American Indian people could benefit from receiving services provided by staff who are professionally trained in identifying and meeting the needs of older American Indian people" (p. 221). The purpose of this project was to provide education and specialized training to reservation-based community representatives who work with people who are elderly and visually impaired and who reside on Arizona reservations.

## Method

The method used in developing the training program will be described in this section. The processes described are development of the training manual and portfolio of resource information, development of the training curriculum, and selection of trainees.

## Development of the Training Manual

A manual (White & Carlise, 1991) was developed to help the reservation-based community representatives understand and review material presented during the workshop and copies were distributed to trainees at workshops in Tucson and Flagstaff. Rehabilitation counselors, rehabilitation specialists, mobility specialists, tribal members, and people with visual impairments were consulted throughout the manual's development. In addition, other training manuals on mobility and daily living skills were reviewed for ideas. Portions of the manual dealing with assistive and technical devices were written to be relevant to rural areas, where running water or electricity is

often scarce. Drawings were used to help clarify and simplify the text. The manual underwent eight revisions before a first draft was completed. Professionals from Arizona tribes, Arizona State Services for the Blind and Visually Impaired (SBVI), and the Institute for Human Development reviewed and made recommendations for improving the manual. The resulting manual con-

***American Indians acquire limitations in activities of daily living at earlier ages than the non-Indian population***

tains drawings and text appropriate for consumers, family members, paraprofessionals, and others to use effectively. It includes information and instructions on definitions of parts of the eye, basic sighted guide instruction, signaling for narrow passageways, going through doorways, traversing stairs with a guide, walking over uneven and dirt roads, trailing, squaring off, seating techniques, forearm and lower body protection techniques, advice and suggestions on staying oriented in rural areas, finding dropped objects, paper money organization, coin identification, making a telephone directory, dialing a telephone, using a pushbutton

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phone, exploring tabletops, food identification, identifying food on a plate, pouring liquids, using flatware, labeling containers, labeling dials, telling time, using writing and signature guides, matching clothing, washing dishes, sweeping a floor, and enhancing useable vision.

The appendix contains information to assist reservation-based community representatives when working with elderly visually impaired people. Included is an orientation/mobility evaluation procedure, an independent living skills assessment process, information on how to make a large print telephone directory, an application for exemption from directory assistance, a braille alphabet form, and a resources form. The resources form was compiled to assist the representatives on where additional information, catalogs, or questions may be obtained when serving elders with visual impairments on reservations.

Of 200 manuals produced, 105 were given to workshop participants. Reservation-based community representatives each received two copies of the manual, one to keep and one to distribute at their discretion. Forty-eight copies of the manual were handed out during the followup phase of the project to consumers, family members of people who were visually impaired, professionals in other reservation organizations, and other interested persons.

## Development of a Portfolio of Resource Information

Portfolios were developed containing information about visual impairments and listing organizations that serve the elderly and/or visually impaired. Each packet contained a senior services directory, *The Vision Shared for the Visually Impaired* (A Transition Resources Directory), a talking books brochure and application, a catalog of aids and appliances for people with visual impairment, a pamphlet of modifications on insulin techniques produced for visually impaired people by the Greater Detroit Society for the Blind, a 2X magnifier, a black felt pen, a description of magnifier characteristics, catalogs, and

a listing of nationwide vision services for people who are visually impaired produced by Science Products for the Visually Impaired.

The senior services directory was distributed to inform trainees of organizations and services available for elders in their region and was used as a guide to discuss the organizations serving people who are elderly and/or visually impaired specific to each representative's reservation. The *Vision Shared Directory* identifies specific state and federal organizations and the services they provide to people who are visually impaired.

Because diabetes is so prevalent on reservations and is a leading cause of blindness, a manual developed by the Detroit Society for the Blind was included in the portfolio. This manual describes how to use staples to make a template for drawing insulin, how to insert a needle into the insulin vial, and how to draw and inject insulin. A black felt pen was provided to emphasize the importance of contrast when working with people who have low vision. Black ink on white or yellow paper helps people with low vision to distinguish letters, numbers, pictures, etc.

## Development of the Training Workshop Curriculum

In August 1990, a meeting was conducted at the Arizona SBVI office in Phoenix to discuss the curriculum to be used for the training program and to identify trainers for the workshops scheduled in Tucson and Flagstaff. Because the project was a statewide, cooperative endeavor, those involved included administrators and rehabilitation counselors from SBVI, an administrator, rehabilitation teacher, and orientation and mobility instructor from the Institute for Human Development at Northern Arizona University, a professor from the Special Education and Rehabilitation Department at the University of Arizona, and a trainer from the American Indian Rehabilitation Research and Training Center (AIRRTC) at Northern Arizona University.

The following eight content areas were identified to be included in the curriculum:

- Physiology of the Eye
- Techniques of Mobility (sighted guide)
- Techniques of Daily Living
- Implications of Blindness
- Technical Aids and Devices
- Social Service Agencies and Information
- Cultural and Rural Issues
- Concerns of the Elderly.

An agenda was established with these main topic areas as guides. Trainers who had expertise related to the identified topics were identified during the meeting and were later contacted and asked to participate in the workshop. Because two workshops were to be conducted, two sets of trainers were identified. Each trainer who agreed to participate was sent a list of the objectives and expected training outcomes to ensure consistency across the two workshops. Emphasis was placed on providing a format and climate for the representatives to be active participants and not passive receptors of information.

## Selection of Key Personnel to Participate in the Training

Because trained professionals indigenous to each reservation and trained in the field of visual impairments are virtually nonexistent, tribal community health directors and directors of programs for elders and social services were contacted to identify interested reservation-based community representatives who already work in the systems that provide services to American Indian elders.

Fifty trainee recruitment packets were sent to representatives of the 21 recognized tribes in Arizona. The list of names and addresses was created from various sources, including tribal leaders, the AIRRTC at Northern Arizona University, and the SBVI.

Two hundred people were identified as potential trainees. These individuals were sent an application letter as well as



a brochure explaining the project. Fifty-one people returned the self-addressed stamped envelope indicating an interest in the program. Those individuals represented 14 of the 21 tribes in Arizona. The majority (31) of the returned applications came from tribal health programs and Indian Health Services. Sixteen application forms were returned by people who worked for senior citizens centers or other special services. Four persons employed by SBVI and who work for the Rural Elderly Blind program returned applications. Applications were not received from six tribes.

## Results

First, results are presented concerning the training program for community representatives to provide independent living skills to those who are elderly and visually impaired. Next, the followup inservice training for the reservation-based community representatives, consumers, family members, and tribal officials is discussed, including a description of the numbers of people with visual impairments served by the trained representatives. Finally, plans for continuation of project activities are discussed.

## Training Program for Reservation-Based Community Representatives

A total of 38 people attended the first phase training workshops in Tucson and Flagstaff. The trainees represented 12 Arizona tribes. Twenty-five individuals worked in tribal health departments, eight were from tribal senior citizen programs, four represented the Rural Elderly Blind Program of the SBVI, and one person worked in a tribal group home for people with developmental disabilities.

An ophthalmologist provided information concerning physiology of the eye and issues related to eye disease and eye care. A psychologist discussed problems relating to family systems involving an individual who is visually impaired. A gerontologist provided in-

formation on elderly needs and concerns. The latest array of technical and low vision equipment were demonstrated by a representative from a local company, and trainees were encouraged to try out this equipment. Cultural issues were presented by an American Indian researcher from the AIRRTC. Various social agencies, such as Native Americans for Community Action, gave brief overviews of their services. Mobility specialists taught and

*Mobility specialists taught and practiced sighted guide skills with the trainees and discussed issues related to independent travel.*

practiced sighted guide skills with the trainees and discussed issues related to independent travel. Rehabilitation specialists taught home, personal, and communication management skills.

The rehabilitation specialists also displayed various aids available for people with visual impairments. Many of the devices were provided for trainees to use with people on their reservations. Each representative also received bold line writing paper, an envelope writing guide, a signature guide, a check writing guide, a letter writing guide, Hi-Marks, a magni-guide, a medicine bottle opener, a safety food turner, a hot pan grip, an inner lip plate, oven mitts, a magnifier, low vision playing cards, a pill organizer, a large print telephone dial, and one 33-inch and one 36-inch orthopedic folding cane. The trainees were given adequate time to practice using these devices with people who are visually impaired. They were also able to practice their newly acquired skills on each other before using these skills to benefit their clients.

There were two workshops, each lasting 5 days. Reservation-based com-

munity representatives from the southern and central tribes were invited to the Tucson Workshop at the Arizona State School for the Deaf and Blind from February 25 to March 1, 1991, and representatives from the northern tribes were invited to the Flagstaff Workshop at Northern Arizona University on March 18–22, 1991.

Fifteen trainees representing six tribes participated in the Tucson workshop where they practiced their skills with nine visually impaired elders who had volunteered from the Tucson Association for the Blind. Their Practicum was held at the Tucson Center for the Blind.

Twenty-three representatives from six northern Arizona tribes participated in the Flagstaff Workshop and practiced their skills with six residents of Flagstaff with visual impairments.

The practicum at both workshops provided a valuable learning experience for the representatives. Many of the trainees identified the practicum as one of the most valuable experiences of the workshop.

The knowledge and skills acquired during the 1-week training sessions were competency based. The learning outcomes specified in the pretest/post-test questions were matched to the learning outcomes described in the objectives. The pretest/post-test consisted of 40 multiple choice questions. The pretest group mean for the trainees was 17 and the post-test group mean was 31. The difference between the pretest and post-test means was significantly different,  $t(37) = -15.44$ ,  $p < .0001$ .

## Followup Inservice Training

Followup inservice training was provided for those completing the Tucson and Flagstaff workshops and consisted of two telephone consultations and one meeting on the reservation that included inservice training for tribal members. The followup training focused on needs specific to the reservation and helped to enhance training areas that needed more attention and improvement, correct misunderstandings, and reinforce the use of techniques learned at the workshop. The inservice



training focused on the same curriculum as the workshop. Overall, community inservice training was provided to 17 tribes through 23 onsite visits. Sixty-two percent of those who attended were people with visual impairments or relatives of people with visual impairments, 25 percent were Indian Health Services representatives, 10 percent were senior citizen center representatives, and the remaining 3 percent were from various agencies.

**A total of 211 people with visual impairments—or an average of 5.76 persons per trainee—were served by the trained reservation-based community representatives.**

Overall, 282 people attended at least one of the 23 inservice training sessions on the reservations. Seventy-one of the participants were Indian Health employees, of which 3 were nurses and 51 were Certified Health Representatives. One hundred seventy-six were elderly visually impaired or relatives of people who were visually impaired. Twenty-eight people who attended one of the inservice sessions worked for senior citizen programs or centers. One person attending the Tohono O'Odham session was a children's home supervisor; another was a supervisor of developmental disability services. A delegate from the tribal chairman's office of the Hopi Tribe attended one of the training sessions at Moencopi. Four other persons worked for the SBVI Rural Elderly Blind Program.

Some of the representatives who attended the workshop and inservice followup conducted their own inservice training for tribal members. Two representatives from the Navajo Tribe presented three sessions, while one representative from the Hopi Tribe conducted two additional sessions.

## **People with Visual Impairments Served by the Trained Community Representatives**


A total of 211 people with visual impairments—or an average of 5.76 persons per trainee—were served by the trained reservation-based community representatives. The numbers served by tribe were: Fort Apache, 6; Fort McDowell, 2; Fort Mohave, 8; Gila River, 9; Hopi, 20; Kaibab, 6; Navajo, 121; Pasqua Yaqui, 3; Hualapai, 10; Salt River, 16; San Carlos, 8; and Tohono O'Odham, 2.

## **Continuation of Project Activities**

Because this training project was funded for only 1 year, efforts were made to identify ways to maintain the momentum of services to American Indian elders with visual impairments. Administrators from the SBVI planned followup activities to ensure that the reservation-based community representatives would continue to develop skills to work more effectively with their clients. These followup activities are part of a grant titled, *Independent Living Services for Older Blind Individuals Program*, which was funded under Title VII, Part C, of the Rehabilitation Act, as amended. Activities under this grant included additional training for the representatives in 1992, 1993, and possibly 1994. In addition to these activities, the participating tribes were allocated approximately \$300 per year to purchase assistive materials and equipment.

## **Discussion**

A training model was developed and implemented to train indigenous personnel in skills needed to aid American Indian elders with visual impairments. The model emphasized training tribal members who were already working for health and social systems within the tribe and followed methodology used in action research (Lewin, 1948; Whyte, 1991). From a psychological ecology perspective, training members of the tribes ensured ready access to tribal elders who were visually impaired

and circumvented distance difficulties and language and cultural differences that might have inhibited rehabilitation interventions. Additionally, training people already within the services system was valuable in promoting culturally relevant programs that encourage networking within tribal agencies. When formal services are provided through state agencies or other non-tribal entities, the services tend to be sporadic, poorly utilized by the tribe, and use little or no networking. McNeely and Colen (1979) noted that because formal professional services are hindered by the lack of indigenous staff, informal networks are important in identifying persons at risk, determining needed services, and providing services. Litwak (1985) noted that members of the informal process are typically indigenous workers and these workers are invaluable because they are regularly members of both formal and informal groups and are in touch with community members. Training tribal members ensured that persons within the community had the knowledge and skills to assist individuals who are elderly and visually impaired. These persons also are used as contacts for state agency personnel who also serve people who are visually impaired. Collaborative efforts with the Arizona State Services for the Blind and Visually Impaired will help ensure the continuation of benefits gained from this project. 

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The authors gratefully acknowledge Ed House and Dave Beard from the Arizona Services for the Blind and Visually Impaired, Dr. Dan Head from the University of Arizona and Darlene Phillips for their assistance in the coordination of this project.

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*Continued on page 37*



# Who Are They?

## some answers from a survey of Javits-Wagner- O'Day employees

Beverly L. Milkman  
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*This article discusses the recent national Javits-Wagner-O'Day (JWOD) population survey. Despite the age and scope of the program, the survey described here was the first survey of the entire JWOD population ever conducted. This new study analyzes basic demographic data as well as information relating to employment and wages, benefits, competitive job placement, and residential living arrangements. As a consequence, the research provides insights regarding the JWOD Program's impact on its participants.*



David Schafebook adds some sparkle to the Shoprite World Class Store in Whitehall, Pennsylvania, where he is competitively employed as a customer service attendant.

It would have been difficult for David Schafebook to obtain competitive employment in the days before the Javits-Wagner-O'Day (JWOD) Program. A customer service attendant at his local Shoprite store, Mr. Schafebook is diagnosed as having mild mental retardation. Using the custodial skills he learned as part of a JWOD service crew,

Mr. Schafebook has become a model employee and earns excellent reviews from his supervisors.

The JWOD Program was established over 50 years ago and today employs and trains over 23,000 Americans with disabilities—people like Mr. Schafebook—while it provides the Federal Government with quality products and services



at reasonable prices. Across the United States, over 500 nonprofit agencies employing people who are blind or have other severe disabilities participate in the JWOD Program.

## Background

The JWOD Program is administered by the Committee for Purchase From People Who Are Blind or Severely Disabled, an independent federal agency composed of 15 Presidential appointees and a small staff. Eleven of the members, including the Commissioner of the Rehabilitation Services Administration (RSA), represent federal agencies; most are involved in procurement-related activities. The remaining four members are private citizens representing the interests of people who are blind or have other severe disabilities.

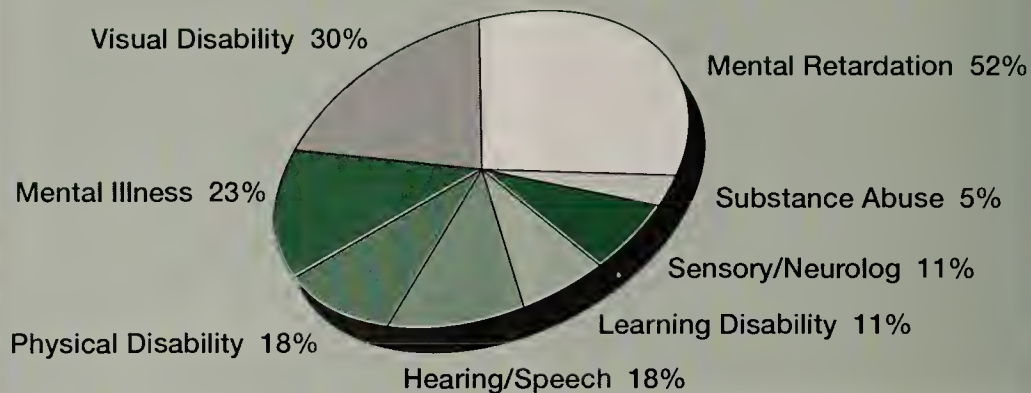
The committee decides which products and services the Federal Government will buy from nonprofit agencies employing people with disabilities. Federal agencies must purchase items placed in the JWOD Program from the nonprofit agencies designated by the committee. The committee also determines the fair market prices to be paid for these items.

Two central nonprofit agencies, National Industries for the Blind (NIB) and NISH, facilitate the participation of individual nonprofit agencies in the JWOD Program.<sup>1</sup> NIB and NISH help identify supplies and services to be included in the program, provide technical and financial assistance to individual nonprofit agencies, and submit pricing recommendations to the committee. The committee's staff, NIB, and NISH work together to ensure that

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## Types of Disabilities in the JWOD Population



Exceeds 100% due to inclusion of multiple disabilities.

JWOD-participating agencies comply with all committee regulations, including requirements that concern the populations to be served. The three organizations also work jointly in developing projects such as the JWOD population survey.

## Methodology

The research was conducted in the fall of 1991, using both a mailed survey of agency records and onsite interviews. Questionnaires were mailed to approximately 10 percent of the JWOD population at 417 participating nonprofit agencies. The response rate was an exceptionally high 95 percent, for a total of 1,657 completed. A total of 218 onsite interviews were conducted at 17 of the nonprofit agencies, a subset of the mail questionnaire population. More interviews took place at NISH-affiliated agencies than at NIB-affiliated agencies, as their employees make up a larger proportion of the total JWOD population.

## Population Characteristics

The main objective of the survey was to identify the types of disabilities represented in the JWOD population. The results show that:

- 51.6 percent have mental retardation;

- 30.1 percent have a visual disability;
- 22.9 percent have a mental illness;
- 17.9 percent have a physical disability;
- 11.2 percent have a sensory/neurological disability;
- 11.0 percent have a learning disability;
- 8.6 percent have a hearing disability;
- 8.6 percent have a speech disability; and
- 5.4 percent have an alcohol or substance abuse disorder.

The total exceeds 100 percent because nearly half of the people served by the JWOD Program (46.6 percent) have multiple disabilities. Nearly three-quarters (73.6 percent) of the JWOD workers were born with their primary disabilities. However, over 20 percent of workers whose primary disability is blindness became disabled after the age of 21, about twice as many as workers whose primary disability is not blindness.

The basic demographic data indicate that about two-thirds of JWOD Program participants are male, and most of the workers are between 25 and 34 years of age. Two-thirds of JWOD employees have never been married, and just over one-half of the population re-



ceived no vocational training before entering one of the nonprofit agencies.

The data show that Caucasians make up the largest classification of JWOD workers, at 63 percent, followed by African Americans, at 28 percent, and Hispanic people, 7 percent. It should be noted that the percentage of African Americans in the JWOD population is much higher than that in the general work force. As for education, one-third of JWOD employees have high school diplomas, and another third have some high school experience. About 7 percent have college or postgraduate experience.

Most JWOD employees were unemployed or underemployed before their referral to the program; 76 percent were not working full time before entering a JWOD nonprofit agency. Referrals usually come from a state's department of vocational rehabilitation or the state agency for mental health.

## Employment

The JWOD Program provides jobs for a group of people whose rate of unemployment is extraordinarily high. "Two-thirds of all disabled Americans between the age of 16 and 64 are not working," according to the *ICD Survey of Disabled Americans: Bringing Disabled Americans into the Mainstream*, Louis Harris and Associates (1986). That figure is now closer to 70 percent, according to 1991 Current Population Survey (CPS) data. Among people with disabilities who are employed, the CPS found that only 20.1 percent work full-time schedules. On the other hand, the majority of JWOD employees work full time, mainly on service, manufacturing, or assembly-related jobs. For some of these workers, full-time employment means working fewer than 40 hours a week due to the severity of their disabilities.

Commodities are generally produced onsite and include office supplies, cleaning products, furniture, paints, and textiles. Most of the NIB-affiliated agencies concentrate on the manufacturing or assembly of these items, often under the SKILCRAFT trade name.



*Alberto Torres, pictured with his guide dog, Greg, develops about 150 X-rays per day as a darkroom technician for the Bronx Municipal Hospital Center.*

Services are more often performed by NISH-affiliated agencies, and include both janitorial/custodial and grounds maintenance contracts per-

formed at federal buildings, shelf-stocking at military commissaries, food service, and clerical work. These jobs are usually performed in settings integrated



with federal employees, separate from the nonprofit agencies' headquarters.

The total sales of these commodities and services in FY 1992 were \$75.6 million. This money covers both direct and indirect labor salaries, which can also be provided by people with disabilities. It also pays for raw materials and equipment, and approximately 4 percent goes to NIB and NISH for administrative and technological support.

During fiscal year 1992, the total number of direct labor hours worked by people who are blind or have other severe disabilities was 18.1 million. For the most part, this number has steadily increased since the program's inception, and record-breaking years have occurred since 1988.

The JWOD survey looked at longevity of employment at participating nonprofit agencies. Overall, one-third of JWOD employees have been working at their current agencies from 1–5 years. Twenty percent have been with their agencies for 10 or more years, while another 20 percent have been employed less than 1 year. The duration of employment tends to be slightly longer for employees working in NIB-affiliated agencies, partially due to the fact that NISH-affiliated agencies tend to make more placements into competitive employment.

## Compensation

In determining compensation, productivity is a major factor. Wages are based on either an hourly rate, a piece rate, or a combination of the two. Levels of productivity are generally determined by time studies, comparing an employee's performance with an established time standard. The survey shows that:

- 20 percent of the JWOD population is 100 percent productive or higher;
- 44 percent of the JWOD population is 60 to 100 percent productive;
- 29 percent of the JWOD population is 20 to 60 percent productive; and

- 7 percent of the JWOD population is less than 20 percent productive.

Along with productivity, JWOD wages are also determined by the prevailing wage rates in the area. JWOD wages range from just under \$1 to more than \$11 per hour. In fiscal year 1992, the total direct labor wages amounted to \$95.9 million, with JWOD jobs often paying more than the federal minimum hourly wage. In fact, 56 percent of JWOD employees make the minimum wage or better, even though only about

***Family support in particular was found to have a high correlation with employee interest in competitive placement.***

20 percent work at full productivity. The direct labor average hourly wage in FY 1992 was \$5.28 (up nearly 7 percent from the previous year). Of those participants who do earn less than the minimum wage, there are more than twice as many NISH/JWOD employees as there are NIB/JWOD employees; this to some extent reflects the types of disabilities (e.g., mental retardation) and lower productivity levels within the NISH population.

While 95.5 percent of JWOD employees interviewed said they are currently paying income taxes, almost two-thirds were *not* paying income taxes before entering the nonprofit agency.

## Financial Assistance

Benefits and assistance provided to employees is another area the JWOD survey examined. Seventy-two percent of JWOD workers said they get some type of financial benefit. Within this

group, approximately 33 percent receive Supplemental Security Income (SSI) payments; 29 percent receive Medicaid or Medicare benefits; and 20 percent receive Social Security Disability Insurance (SSDI) benefits. In addition, 36 percent receive multiple benefits and 29 percent have reduced the number of benefits they receive since entering the program.

JWOD employees were also asked if they limit the number of hours they work in order to remain eligible for other benefits. Ninety-five percent said they did not intentionally limit their work hours in the last year; the 5 percent who did reported they were worried about losing their Social Security or other benefits. This response differs from anecdotal evidence, and is a subject that the committee plans to research in the future.

While the mission of the JWOD Program is to generate employment and training for people who are blind or have other severe disabilities, many participating nonprofit agencies provide other services or assistance to their employees, such as transportation, housing, and counseling. More than 91 percent of those surveyed indicated they received job training in their current or previous position at the JWOD agency.

The assistance available depends on how large the nonprofit agency is and the resources it has available. For example, the Seattle Lighthouse for the Blind offers a prevocational program, daily living skills training, senior citizen services, and a program specifically designed to serve people who have both visual and hearing disabilities. The Exceptional Children's Foundation in Los Angeles even has a fine arts program for its clients with mental illness or mental retardation. Most JWOD agencies offer placement services internally, while the remainder make outside placement aid available.

## Competitive Employment

On an individual level, David Schafebook made the transition from JWOD employment to a full-time placement at the Shoprite grocery store. On



a program level, competitive employment is an ultimate goal whenever possible. In the past, JWOD placements have numbered about 1,300 to 1,600 per year, out of about 20,000 people in the program. Most recently, 1,327 JWOD workers were placed during FY 1992.

Alberto Torres represents another competitive placement success story. Mr. Torres has been visually impaired since birth, and became totally blind 13 years ago due to an inflammation of his optic nerve. He moved into competitive employment as a darkroom technician at the Bronx Hospital Municipal Center after working many years at Lighthouse Industries for the Blind in Long Island, New York. Today, he braves a 2-hour commute each way to his job developing x-ray film, preparing solutions, and maintaining the stock of supplies.

Employees who have successfully gained competitive positions are not included in the JWOD survey data, as they are no longer in the program. Consequently, the survey results do not reflect the accomplishments of JWOD employees and agencies with respect to successful placements in competitive jobs. It is important to realize that success in competitive employment depends not only on competence, but on job availability and employee interest as well. Family support in particular was found to have a high correlation with employee interest in competitive placement.

According to the survey, no attempt has been made to place over two-thirds of the current JWOD employees. Reasons for this include a lack of interest or capability on the part of the employee or a lack of suitable jobs in the community. In some cases, the nonprofit agencies provide the best job in the community for the employee. Of the employees who were placed but returned to the agency, many were laid off because of a lack of work, while others decided they preferred working at the nonprofit agency.

## Residential Living

The survey also collected information on JWOD employees' current liv-

ing arrangements. The largest percentage live with their relatives, about 36 percent. Almost 20 percent live with their spouses and/or children, and another 17 percent live alone. Interestingly, the survey reports that two-thirds of the JWOD population aged 75 and older live by themselves, which is significantly more than the general population; however, the sample size for this group is fairly small. Additionally, more JWOD workers who are blind live independently than do those with other severe disabilities. But less than 2 percent of the entire JWOD population live with residential supervision by health care workers.

Since entering the JWOD Program, about one-third of the employees report they are living more independently. As promoting independence is one intention of the program, this data is indicative of progress toward the overall JWOD goals.


## Conclusion

The survey findings emphasize that the committee is serving its intended beneficiaries—people who are most severely disabled—and of this group, those who are unemployed. These findings confirm that JWOD contracts provide employees with disabilities an opportunity to earn much better wages than would be possible in the absence of federal contracts. And while the program's focus is helping people with severe disabilities, the Federal Government also gains in the exchange, as it pays fewer benefits to people with severe disabilities who work on JWOD contracts.

The survey will be of great value in helping the committee determine how to better serve the JWOD population and providing a database from which to track future changes. For example, the impact of the Americans with Disabilities Act (ADA) on JWOD employment and competitive placement efforts remains to be seen. The survey tells us that most JWOD employees are currently unaware of ADA and its implications regarding their future employment.

In the last few years, sales and employment data show that the program

has been growing dramatically. Specifically, FY 1991 was a year of major growth due to large military purchases for Operation Desert Shield/Storm. In light of the recent Department of Defense cutbacks, the JWOD Program will face more challenges in continuing to provide employment for the increasing number of people with severe disabilities who want to work.

The JWOD Program has served as a catalyst to generate countless jobs for Americans who are blind or have other severe disabilities since the program's inception over 50 years ago. Almost half of the population served today has more than one disability, and this trend is expected to continue in the future. Rehabilitation professionals should consider the employment opportunities created through JWOD contracts as a placement option for the people with disabilities they serve. JWOD work makes meaningful training, self-confidence, and increased independence a reality for employees. These jobs can serve as stepping stones on the road toward independence, integration, and self-sufficiency. 

## Notes

<sup>1</sup> See *American Rehabilitation*, Spring 1991: "The JWOD Program and NISH," p. 14, for related article.



For additional information about the JWOD Program, or how to support it, contact Kimberly Putnam of the committee's staff at (703) 603-7740.

Copies of the full survey or its highlights are available.





# Screening for Undetected Substance Abuse Among Vocational Rehabilitation Clients

Diana M. DiNitto  
A. James Schwab



Alcohol and other drug disorders (commonly referred to as substance abuse or chemical dependency) are problems frequently encountered in the field of vocational rehabilitation (VR). Nationwide, in fiscal year 1990, 215,924 clients of state VR agencies were successfully rehabilitated. Of these, 23,903, or 11.1 percent, had a primary disability of substance abuse or dependence, and 8,031, or 3.7 percent, had a secondary disability of substance abuse or dependence. In fiscal year 1990, the Texas Rehabilitation Commission (TRC), Texas' primary VR agency, rehabilitated 17,110 people. Of these, 2,641, or 15.4 percent, had a primary or secondary disability or both identified as substance abuse or dependence. While the remaining 84.6 percent did not have a primary or a secondary disability of substance abuse or dependence, little is known about whether there are undetected alcohol and drug problems among these clients which might hamper successful VR outcomes.<sup>1</sup>

Substance abuse or dependence may go undetected among clients for at least two reasons. The first is denial of these problems by substance abusers and their loved ones, a topic addressed in virtually every textbook on substance abuse. The personal experiences of VR professionals may also affect their perceptions of these problems. The second reason for undetected substance abuse is that like other helping professionals,

VR counselors have been described as lacking adequate knowledge of substance abuse and as having inadequate preparation to work with this clientele (Dickman & Phillips, 1983; Greer, 1989). They may also give low preference to substance abuse clients (Marson, 1978; Allen, Peterson, & Keating, 1982; Goodyear, 1983). Although recent evidence indicates that knowledge and attitudes of professionals about chemical dependency may be changing in a positive direction (Taricone & Janikowski, 1990), failure to detect substance abuse may account for some clients being labeled rehabilitation failures rather than successes. The question of whether there is inadequate identification of alcohol and drug problems among VR clients concerned TRC and the Texas Commission on Alcohol and Drug Abuse enough to prompt the agencies to jointly sponsor research to investigate this issue. The study was conducted by faculty of The University of Texas at Austin, School of Social Work.<sup>2</sup>

## Study Methodology

More specifically, the study described in this article was designed to address four questions:

- Is there undetected substance abuse among TRC clients?
- What types of instruments are most useful in screening for substance abuse among VR clients?
- Are clients with particular disabilities more likely to be undetected substance abusers?
- Does undetected substance abuse affect case closure status? In order to answer these questions, a field study design with quantitative and qualitative components was selected. Undetected

substance abuse was defined as an alcohol or drug problem that was not identified by TRC as a primary or secondary disability of the client.

The researchers asked VR counselors in one district in central Texas to refer to them active clients, age 18 and older, who had been accepted for TRC services. Cost factors made statewide sampling impractical. Clients younger than 18 were excluded because additional consent from parents or guardians would have been required. Counselors were asked to refer clients whether or not they had a substance abuse or dependence disability, and clients with all types of disabilities were included. Research team members were generally not informed in advance of the client's disability. In some cases, the disability was obvious because the client was interviewed at a halfway house or sheltered workshop. Inclusion of clients with substance abuse disabilities allowed the researchers to determine if the instruments selected to detect substance abuse were accurately identifying those already known to have problems with alcohol or other drugs. Interested clients met with a research team member who described the study in greater detail, including confidentiality procedures. The researcher emphasized that the client's decision whether or not to participate would not affect his/her relationship with TRC.

To determine what type of instrument might be most useful in identifying substance abusers, the researchers considered a number of possibilities. Two different types of instruments, the Addiction Severity Index (ASI) and the Substance Abuse Subtle Screening Inventory (SASSI), were selected. ASI is a



structured interview and SASSI is a brief, self-administered, screening device (these instruments are discussed in greater detail below). The research team members who administered the instruments were qualified clinicians and received special training for the study.

For the most part, the team members were able to alternate the use of the instruments so as not to introduce bias according to which clients took the SASSI and which took the ASI. In a few cases, the SASSI was used because the client did not have enough time to complete the ASI. Only the SASSI was used with deaf clients. A skilled sign language interpreter assisted. Deaf clients were not asked to complete the ASI, because signing the interview and translating clients' responses would have taken more time than other clients were asked to contribute and more time than clients might have been able to devote. The researchers could not identify any substance abuse screening instrument that had been validated with deaf people.

Instruments were administered over a 6-month period from November 1990 to May 1991. The TRC automated client data base was also used as a source of information. Clients also agreed to allow the researchers to review their case files. This allowed the researchers to determine if the client may have had a third disability of substance abuse or dependence (third disabilities are not entered on the automated data base) or if the counselor's notes indicated an alcohol or drug problem.

## Instruments

The Addiction Severity Index was "developed to fill the need for a reliable, valid, and standardized diagnostic and evaluative instrument in the field of alcohol and drug abuse" (McLellan, Luborsky, Woody & O'Brien, 1980, p. 26). It has been widely used in substance abuse treatment and research and can be administered by helping professionals from virtually all disciplines with appropriate training (Grisom & Bragg, 1991). Administration generally takes a minimum of 30 min-

utes; but, with people who have communications disabilities or those who have significant problem histories, administration can take longer.

The ASI covers seven areas of the client's life: medical, employment and economic support, alcohol use, other drug use, legal, family and social, and psychological or psychiatric (McLellan et al., 1980). A score indicating the severity of the client's current problems can be computed for each of the seven areas (McGahan, Griffith, Parente, & McLellan, 1990). The ASI has been shown to be reliable and valid among substance abusers applying for treatment (for details see McLellan et

***The SASSI takes about 10 or 15 minutes to complete, and it can be easily administered and scored by helping professionals trained in its use.***

al., 1980; McLellan, Luborsky, Cacciola, Griffith, Evans, Barr, & O'Brien, 1985; Fureman, Parikh, Bragg, & McLellan, 1990). It has been used in criminal justice settings and with mentally ill and homeless people, but reliability and validity with these populations has not currently been established. We are not aware of previously published work in which the instrument has been used with VR clients.

Although the ASI has no classification system (i.e., no normative scores or clinical cutting points) for distinguishing those who have alcohol or other drug abuse or dependence problems from those who do not, it provides substantial information about the individual that can be used to make an assessment. In this study, a panel of three of the research team members (all MSW's certified by the state of Texas, two of whom also have certification in the chemical dependency field) reviewed each client's responses to iden-

tify alcohol or drug problems. While there was a concern that this procedure might overestimate substance abuse problems, the researchers focused on the following responses:

- *Number of years of problem use of alcohol, heroin, methadone, opiates or analgesics, barbiturates, other sedatives, hypnotics or tranquilizers, cocaine, amphetamines, cannabis, hallucinogens, and inhalants.* The ASI criterion for problem use is three or more times a week for 6 months or more, or regular and severe abuse of alcohol or drugs in 2-day binges (Fureman, Parikh, Bragg, & McLellan, 1990, p. 19).

- *The presence of alcohol or other drug-related consequences, such as drug overdose, delirium tremens, episodes of inpatient drug or alcohol treatment, evidence of medical concerns about addiction, and DWI or other alcohol- or drug-related arrests.*

- *Current attendance in outpatient counseling for drug or alcohol rehabilitation or current attendance at Alcoholics Anonymous or Narcotics Anonymous groups.*

Examples of cases that the researchers classified as having alcohol or drug abuse problems were clients who had used illegal drugs for a period of years, had drug overdoses or suicide attempts using drugs, were experiencing problems related to long-term use of pain medications, had been in alcohol or drug detoxification or other drug treatment, expressed worries about their use of alcohol or other drugs, or had other alcohol- or drug-related problems. In an effort to provide a conservative estimate of the number of clients with alcohol or drug problems, certain types of cases were omitted, such as clients with a period of alcohol abuse in high school or college that seemed to be resolved in adulthood. Also excluded were clients with extensive use of prescription medication when it was indicated that use was closely monitored by a physician.

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The SASSI was designed "to serve as an objective screening tool to differentiate substance abusers from non-abusers" (Miller, 1985, p. 5-3). Items are at a fifth grade reading level. The SASSI is generally self-administered, but it was read in a few cases to clients with minimal reading skills. The instrument contains two parts. The first is a set of "subtle" items and the second is a set of "face valid" items. The subtle items do not appear to be measuring substance abuse or dependence and are intended to make the measure "fake-proof" or "lie-proof." It is recommended that the subtle items be administered before the face valid items to minimize the defensiveness of the respondent.

The subtle items comprise six scales (Miller, 1985).

- *The Obvious Attributes Scale* is intended to measure the openness or the willingness of the client to admit to symptoms or problems.

- *The Subtle Attributes Scale* was developed to minimize intentional misrepresentation by the client and apparently measures a predisposition to alcohol or drug dependency.

- *The Denial Scale* was originally designed to identify the client's defensiveness to test-taking; very high scores may also suggest other personal or emotional problems, such as feelings of personal worthlessness.

- *The Defensive Abuser vs. Defensive Non-Abuser Scale* is used with the Denial Scale score in determining if respondents are abusers or whether their responses are those of a defensive non-abuser.

- *The Alcohol vs. Drug Scale*, thought to be the weakest scale, is intended to show whether the client prefers alcohol or other drugs.

- *The Family vs. Controls Scale*, also one of the weaker scales, can be interpreted as a co-dependency scale; it determines how similar an individual is to members of families in which one or more individuals is chemically dependent.

The second part of the SASSI is comprised of two scales, *the Risk Prediction Scale for Alcohol* and *the Risk Prediction Scale for Drugs* (also known as *the Face*

*Valid Alcohol Scale* and *the Face Valid Drug Scale*) developed by the Indiana Division of Addiction Services (Morton, 1978; Miller, 1985; also see Cooper & Robinson, 1987). These items clearly ask questions about alcohol and drug use and the consequences of this use. Respondents were asked about their alcohol and other drug use during the last 6 months. The effectiveness of the SASSI is increased when these two face valid scales are used in combination with the subtle items.

The SASSI takes about 10 or 15 minutes to complete, and it can be easily

***Of the 86 clients for whom TRC had not identified a primary or secondary disability of substance abuse or dependence, 38.4 percent (33 clients) were identified by the researchers through use of the ASI as presenting an alcohol or drug problem.***

administered and scored by helping professionals trained in its use. Respondents are classified as chemically dependent or not, based on a set of explicit decision rules. The classification of "defensive non-abuser" helps to rule out false positives (i.e., to minimize the likelihood that people are inappropriately identified). Additional guidelines are available to identify those who do not appear to be chemically dependent but may be substance abusers (Knot, no date). The SASSI elicits little of the client's general life history. It is a brief screening tool and in clinical practice should be used with a more thorough social history or other tools in order to make a definitive assessment.

Miller (1985) reports the accuracy rate of the SASSI to be between 89 and 97 percent with a miss rate of 5 to 10 percent (also see The SASSI Institute, 1990; Cooper & Robinson, 1987; Craeger, 1989). Cooper and Robinson (1987) re-

port that the SASSI has a concurrent validity of .62 with the MacAndrew Alcoholism Scale (MacAndrew, 1965).

The researchers developed a form for the collection of qualitative data from clients' case files so that any information on substance use, abuse, or related problems could be systematically recorded. Qualitative data were obtained from a random sample of one-fourth of the clients who participated in the study. Each file was read by two or three researchers to verify the information and to provide a reliability check.

## **Representativeness of the Sample**

A total of 254 clients who completed the ASI or the SASSI and whose social security numbers could be matched with the TRC data tape were used in the final analysis (116 took the ASI and 138 took the SASSI). To determine the representativeness of the sample, the participants were compared with the population of TRC closed cases for the previous fiscal year, 1990. (Data on current clients had not yet been compiled, and there was no reason to believe that client characteristics had changed substantially over this brief time period.)

The clients that participated in the study were quite similar to the population of clients whose cases were closed during FY 1990 with respect to most variables, such as gender, marital status, family composition, criminal record, and other demographic characteristics. African American, Hispanic, and Asian clients were underrepresented in the study, while white and American Indian clients were overrepresented. Clients with a TRC-identified primary disability of substance abuse or dependence were slightly underrepresented in our study sample, and those with a secondary disability of substance abuse or dependence were overrepresented. While the study participants are not an exact match of the client population, they generally do reflect a broad cross section of TRC's clientele.



**Table 1**

**Number of Addiction Severity Index (ASI) Respondents Who Were Not Identified by the Texas Rehabilitation Commission (TRC) as Having a Primary or Secondary Disability of Chemical Abuse or Dependence (n = 86) Who Reported Alcohol or Other Drug Use**

	Number Who Used in Past 30 Days	Number with One or More Years of Use During Lifetime <sup>a</sup>
Alcohol Use	39	46
Alcohol Intoxication	15	38
Heroin	0	4
Methadone	0	0
Opiates/Analgesics	14	20
Barbiturates	2	4
Sedatives	4	11
Cocaine	0	9
Amphetamines	0	13
Cannabis	6	20
Hallucinogens	0	5
Polydrug	2	23

<sup>a</sup> Use is defined as three or more times a week or regular and severe abuse in 2-day binges. A minimum of 6 months is coded as a year on the ASI.

## Study Results

Based on the ASI and SASSI results, the researchers classified each participant as to whether or not they appeared to have an alcohol or drug problem. The researchers then matched the clients with the TRC data base which contained their primary and secondary disabilities. A comparison was also made with the qualitative data.

## ASI Results

Of the 116 clients who took the Addiction Severity Index, TRC had previously identified 30 as having a primary or secondary disability of substance abuse or dependence.

## Clients' Drug Use

Of the 30 clients with a TRC designated primary or secondary disability of substance abuse or dependence, four

reported use of alcohol or other drugs in the 30 days prior to their interview.

Of the 86 clients for whom TRC had not identified a primary or secondary disability of substance abuse or dependence, 36 reported no alcohol or other drug use in the last 30 days. Of the 50 remaining clients, 30 reported use of alcohol only. Of these, 10 reported use at least to the point of intoxication. Twenty clients reported some use of at least one drug other than alcohol or some combination of alcohol and other drug use in the last 30 days. The number of clients who used alcohol and each type of drug in the last 30 days is reported in Table 1.

Lifetime figures show that 46 of the 86 clients reported using alcohol approximately three times a week or more during a period of 6 months or longer. (The longest period of this use was 34 years.) Thirty-eight clients reported a period of 6 months or more where they drank to intoxication. Slightly less than

half of the 86 clients not identified by TRC as having chemical abuse or dependence disabilities reported no substantial history of alcohol use or abuse.

Among those who had a history of drug use, cannabis and opiates or analgesics were the most often used drugs (20 clients reported problem use in each of these categories). No extensive use of methadone was reported. Eleven clients reported a history of sedative use, and four reported a history of barbiturate use. Substantial use of cocaine was reported by 9 clients, and 13 reported substantial use of amphetamines. Five clients reported extensive use of hallucinogens. Twenty-three clients were classified as polydrug abusers (i.e., they had used more than one drug at the same time during at least a 6-month period). Some of the drug use reported was frequent use of prescribed medication, such as analgesics.

## Detected and Undetected Substance Abuse

Clients who took the ASI were placed into four groups:

- those that TRC identified as having a primary or secondary disability of substance abuse or dependence that were also identified by the researchers as having a problem with alcohol or other drug use (referred to below as the "TRC-and-ASI-identified group");
- those that the researchers identified as having a problem with alcohol or other drugs that TRC had not identified as having a primary or secondary substance abuse or dependence disability (referred to below as the "ASI-identified group");
- those that TRC did not identify as having a primary or secondary disability of substance abuse or dependence that the researchers also did not identify as having a problem with alcohol or other drugs (referred to below as the "neither-identified group"); and
- those that TRC identified as having a primary or secondary disability of substance abuse or dependence that the researchers did not identify through use of the ASI (referred to as the "TRC-identified group").



Table 2 shows that 29 cases (25 percent of the 116 cases) fell into the TRC- and ASI-identified group. Thirty-three cases (28.4 percent) fell into the ASI-identified group, and 53 (45.7 percent) of the cases into the neither-identified group. Only one case (.01 percent) fell into the TRC-identified group. (In reviewing this ASI form, it may be that the interviewer failed to recognize that this client was not responding accurately to questions about past use of alcohol or drugs or the client's primary or secondary disability may have been miscoded on the TRC computer tape).

Qualitative data were obtained on five of the clients in the ASI-identified group. Four of the files did have some indication of past or present alcohol or drug abuse. In the fifth case, the client's ASI indicated a 19-year history of alcohol use at least to the point of intoxication, but the file did not indicate any problem with alcohol.

In summary, of the 86 clients for whom TRC had not identified a primary or secondary disability of substance abuse or dependence, 38.4 percent (33 clients) were identified by the researchers through use of the ASI as presenting an alcohol or drug problem. Only 1 of the 30 clients identified by TRC with a primary or secondary disability of substance abuse or dependence was not similarly identified using the ASI.

## SASSI Results

A comparison of SASSI and TRC classifications of study participants is reported in Table 3. In 72 (52.2 percent) of the 138 cases, TRC had not identified a primary or secondary disability of substance abuse or dependence; likewise, the SASSI identified neither substance abuse nor dependence in these clients. In 22 (15.9 percent) of the cases, the client scored as chemically dependent on the SASSI, but TRC had not indicated a primary or secondary disability of substance abuse or dependence. In an additional 13 cases (9.4 percent), the client was classified as a chemical abuser (but not chemically dependent) using SASSI guidelines,

<b>Table 2</b> <b>Comparison of Addiction Severity Index (ASI)- and Texas Rehabilitation Commission (TRC)- Identified Cases of Substance Abuse or Dependence</b>			
ASI- Identified— substance abuse or dependence	TRC- Identified substance abuse or dependence		Total
	Yes	No	
Yes	29	33	62
No	1	53	54
Total	30	86	116

<b>Table 3</b> <b>Comparison of Substance Abuse Subtle Screening Inventory (SASSI)- and Texas Rehabilitation Commission (TRC)- Identified Cases of Substance Abuse or Dependence</b>			
SASSI- Identified— substance abuse or dependence	TRC- Identified substance abuse or dependence		Total
	Yes	No	
Yes	27	35	62
No	4	72	76
Total	31	107	138

and TRC had not identified chemical abuse or dependence as a primary or secondary disability. In total, 35 (25.4 percent) of the 138 cases were classified as chemically dependent or chemical abusers by the SASSI, but had not been identified by TRC as having a primary or secondary substance abuse or dependence disability. In 27 (19.6 percent) of the cases, TRC had identified the client as having a primary or secondary disability of substance abuse or dependence, and the SASSI also classified the individual as chemically dependent. In four cases (2.9 percent), TRC had identified a primary or secondary disability of substance abuse or dependence, but the SASSI did not identify the person as chemically dependent or as a chemical abuser.

## Clients with no TRC-Identified or SASSI-Identified Substance Abuse or Dependence

In 35 of the 72 cases in which TRC had not detected a primary or secondary disability of substance abuse or dependence, and the SASSI also did not identify the client as having a chemical dependency or abuse problem, the individual's responses were considered defensive. In a clinical situation these clients would have been asked to repeat the measure to obtain a more accurate reading of whether chemical abuse or dependency might be a problem.

Qualitative data were available on 21 of these 72 cases. In 16, the qualitative data did not indicate any alcohol or drug problems. While some of these



16 clients were taking prescription pain medications, minor tranquilizers, or sleeping medications, no problematic use was reported in their files. In the remaining five cases, however, some indication of current or past alcohol or drug problems was mentioned. One client had long-term sobriety and was still attending a self-help group. In another case, the client had a third disability of alcoholism indicated in the file. Although the SASSI did not classify this client as chemically abusive or dependent, the client's responses were defensive. In the third case, the file indicated problems with alcohol, but the SASSI indicated no problems with chemicals, and the client's responses were not defensive. In a fourth case, one alcohol-related problem (an arrest for Driving Under the Influence) was noted in the file. In the fifth case, the file indicated that the client may have been drinking occasionally while taking prescription analgesics.

### **Clients Identified as Chemically Dependent by the SASSI Only**

Of the 22 clients identified as chemically dependent by the SASSI only, 11 were identified through use of the subtle items only. In the other 11 cases, clients scored high enough on the face valid alcohol or face valid drug scale to classify them as chemically dependent, whether or not the subtle items are considered. These people were rather candid about reporting their use of alcohol and drugs and the consequences of this use. Qualitative data were collected on 5 of these 22. In one of these cases, no substance abuse was indicated in the client's file, but the face-valid alcohol and drug scales on the SASSI indicated a problem. In the second case, the file indicated alcohol and drug problems, but these problems were not listed as a disability of the client. In a third case, the file indicated prescribed medication use for pain but no drug problem; however, the face valid alcohol scale on the SASSI indicated dependence. In the fourth case, the client was identified as chemically dependent from the subtle items. The file indicated that the

client had received substance abuse treatment, but no current disability of chemical abuse or dependence was listed. In the fifth case, the client was identified as chemically dependent from subtle items. This client's file indicated an alcohol-related incident many years ago but no indication of a current problem.

### **Clients Identified as Substance Abusers by the SASSI Only**

Of the 13 clients identified as substance abusers by the SASSI, but not by the primary and secondary disabilities assigned by TRC, 9 were identified by the face valid scales and 4 were classified using the subtle items only. Qualitative data were collected on 3 of these 13 clients; no alcohol or drug problems were identified in their files. However, in one case in which the client was identified through the subtle items, the individual was receiving counseling due to a family history of addiction. It is possible that the SASSI reflected the client's codependency.

### **Clients Identified by TRC Only**

There were four cases in which the SASSI did not detect substance abuse or dependence in a TRC client with a primary or secondary disability of substance abuse or dependency. Two of these clients told the interviewer that they were recovering from chemical dependency and had been sober or "clean" for longer than 6 months. The face valid alcohol and face valid drug scales asked the respondent to report on the last 6 months only. A plausible explanation for why these clients were not classified as chemically dependent by the SASSI is that as a person progresses through recovery, their scores will move toward the normal range, and they therefore will no longer fit the profile of a chemically dependent individual. Qualitative data available from the file of one of these clients did indicate the individual was a recovering alcoholic with several years sobriety. In a third case, the client's responses were defensive and may have been in-

accurate. The fourth case was either a test miss or this client may also have been in recovery and did not offer this information to the researcher.

In summary, 32.7 percent (35) of the clients that TRC had not identified as having a primary or secondary disability of substance abuse or dependence were identified as chemical abusers or chemically dependent using the SASSI. This is very similar to the 38.4 percent of clients who fell into the ASI-only identified group. Like the ASI, the SASSI also appears to have sufficient accuracy in detecting alcohol and drug problems among TRC clients, since 27 (87 percent) of the 31 cases for which TRC had identified a primary or secondary disability of substance abuse or dependence were similarly classified by the SASSI.

### **Clients' Disabilities and Undetected Substance Abuse**

Since the number of clients with some disabilities (for example, diabetes and speech impairments) was quite small, it is not possible to draw conclusions about whether clients with particular disabilities are more likely to have undetected alcohol and drug problems. It may be worthwhile, however, to comment on those primary or secondary disability categories that contain the largest number of study participants: back injuries, limb impairments, and mental disorders.

Fifty-one clients had a back injury as their primary disability and 12 had this as a secondary disability. Nineteen of those with a primary and 3 with a secondary back injury disability (a total of 22 clients) were identified as having an alcohol or drug problem through use of the ASI or the SASSI, but not by TRC. Twelve were identified using the SASSI and 10 using the ASI.

Do these 22 people really have alcohol or drug problems? Perhaps they do not. It may be that they have profiles similar to chemically dependent clients and that an instrument like the SASSI, which makes use of subtle items, is simply reflecting this similarity. However, this does not appear to be the case since nearly all



**Table 4**  
**Addiction Severity Index (ASI)- or Substance Abuse Subtle Screening Inventory (SASSI)- and**  
**TRC- Identified Cases by Closure Status**  
**(N=112)**

	ASI Successful	Unsuccessful	SASSI Successful	Unsuccessful	TOTAL Successful	Unsuccessful
ASI- or SASSI- Identified only	6 54.5%	5 45.4%	10 62.5%	6 37.5%	16 59.3%	11 40.7%
Both ASI- or SASSI- and TRC- Identified	14 70.0%	6 30.6%	11 55.0%	9 45.0%	25 62.5%	15 37.5%
Neither- Identified	12 75.0%	4 25.0%	20 74.1%	7 25.9%	32 74.4%	11 25.6%
TRC- Identified only	0 0.0%	0 0.0%	1 50.0%	1 50.0%	1 50.0%	1 50.0%
TOTALS	32 68.1%	15 31.9%	42 64.6%	23 35.4%	74 66.1%	38 33.9%

of the 12 who took the SASSI were identified through the face valid scales. The clients classified by the ASI also had to give rather clear indications of alcohol or drug use and related problems for the researchers to classify them as having an alcohol or drug use problem.

The ASI and SASSI identified similar numbers of back injured clients with undetected alcohol or drug problems. If these clients had alcohol or drug problems which had been the *cause* of their back injuries, it seems that this would or could have been identified at the beginning of the rehabilitation process. Why were these problems not listed as a disability of the client (assuming that the client has such a disability)? Perhaps these clients developed an alcohol or drug abuse problem as a result of their back injury, and it has not yet been identified by the counselor. Another explanation is that the counselor may not define the client's alcohol or drug use as problematic or this use is not interfering with the rehabilitation process. In some cases, the counselor may be aware of alcohol or drug problems, but a third disability cannot be listed in the computerized data base.

A total of 65 clients had a primary or secondary disability of limb impairment; of these, 10 were identified by the SASSI and 11 by the ASI as having an alcohol

or drug problem not identified by TRC. Possible explanations for why substance abuse problems among this group may go undetected are similar to those described for clients with back injuries.

Among the 43 clients with a primary disability of mental disorder, 12 that had not been classified by TRC as having a substance abuse or dependence disability were classified as having alcohol or drug problems by the ASI or SASSI (5 by the ASI and 7 by the SASSI). There is a growing body of literature on the susceptibility of those with mental disorders to psychoactive drug problems and of those with psychoactive drug problems to mental disorders (Webb & DiNitto, 1991).

Thirty-nine clients had secondary disabilities of mental disorders; of these, five were identified by the ASI and six by the SASSI as having undetected substance abuse. Since these clients already have two disabilities, a third disability identified by TRC cannot be listed on the computerized data base. However, it is noteworthy that 112 clients with no secondary disability participated in this study. Of these clients, the ASI identified 17 and the SASSI identified 18 as having an undetected alcohol or drug problem. Had the counselor identified an alcohol or drug disability in these clients, there

would not have been a problem in entering this into the data base.

In summary, for given disability categories, a substantial number of undetected substance abuse or dependency problems were identified, with similar numbers of these clients identified through the ASI and the SASSI.

### Closure Status and Undetected Substance Abuse

Finally, an analysis was done to determine if undetected substance abuse or dependence made any difference in whether cases were closed successfully or unsuccessfully. At the time these data were collected, 112, or 44 percent, of the 254 participants' cases had closed. Like the overall closure rates for TRC clients, about two-thirds of the cases had closed successfully and the remaining one-third had closed unsuccessfully. However, closure status varied by whether alcohol or drug problems were identified by TRC and the ASI or SASSI, by the ASI or SASSI only, or whether no substance abuse disability was identified (see Table 4). Study participants with no substance abuse or dependence disability identified had the best outcomes; 74.4 percent were successfully rehabilitated (see total columns). Clients whose alcohol or drug problems were



identified by both the TRC and the ASI or SASSI had a successful closure rate of 62.5 percent, followed closely by those whose substance abuse was identified through the ASI or SASSI only (their success rate was 59.3 percent). These results suggest only slightly worse outcomes for those with undetected substance abuse.

As also seen in Table 4, however, this overall pattern was not the same for clients who took the ASI and those who took the SASSI. In both situations, the clients with no alcohol or drug problems identified did best. For those who took the ASI, the clients identified by both TRC and the ASI did almost as well as those with no identified alcohol or drug problems, while undetected substance abusers (identified by the ASI only) did substantially worse. The situation for those who took the SASSI was different. Clients who were identified by the SASSI only did better than those who were identified by TRC and the SASSI. Cell sizes are small, making it impossible to draw conclusions from these data or to speculate about why the results differed for the ASI and SASSI groups.

## Discussion and Conclusions

The ASI and SASSI were both used with little difficulty in this study. In general, they seem suitable for use with VR clients. Few deaf clients participated in the study. While the SASSI has not yet been validated with persons who are deaf, the instrument was easily administered with the use of a skilled sign language interpreter. Several clients with mental retardation had difficulty completing the ASI interview, and their responses were not included in this study. Further administration of the SASSI and the ASI to clients with a range of physical and mental disabilities would help to validate these instruments with a vocational rehabilitation population.

Since both instruments were easily used but differ considerably, choosing one of them (or similar instruments) for use in a VR setting is largely a matter of deciding if a brief, initial screening in-

strument is needed or whether a longer assessment tool that elicits more client history information is preferable. In a VR setting where many clients apply for services, a brief instrument like the SASSI may be used with all clients, followed by an instrument like the ASI if a problem is indicated. Also to be considered is whether the population is likely to be defensive about their alcohol or drug use. If so, the SASSI may prove useful as an initial screening tool. In any case, a definitive diagnosis can only be made by a qualified clinician.

If the results of the ASI and SASSI are correct, there is a considerable amount of undetected substance abuse among TRC

*Clients whose alcohol or drug problems were identified by both the TRC and the ASI or SASSI had a successful closure rate of 62.5 percent.*

clients. The ASI and SASSI identified very similar numbers of undetected substance abusers among the TRC clientele who participated in this study. About one-third of those with no primary or secondary disability of substance abuse or dependence were identified using each of the instruments. The similarity in the number of clients identified lends some confidence that substance abuse was appropriately detected in this study. In addition, in almost all cases, the ASI and SASSI accurately identified alcohol or drug problems in the clients who had TRC-identified primary or secondary disabilities of substance abuse or dependence.

The qualitative data obtained from case files was also useful in this study. In a number of cases in which TRC had not identified a primary or secondary disability of substance abuse or dependence but the ASI or SASSI suggested such problems, the review of case files indicated that counselors had some awareness of these problems. However, counselors may not have investigated

further or apparently do not regard these problems as serious enough to warrant intervention. Perhaps even more interesting were indications of alcohol and drug problems in the case files of some clients for whom neither the primary nor secondary disabilities assigned by TRC nor the researchers identified alcohol or drug problems. The extent to which these problems were ongoing or warranted intervention is not clear. It is not uncommon for people, especially youth, to experiment with alcohol or drugs or for an individual to obtain a single DWI conviction. Perhaps counselors took care to note even temporary, fleeting problems.

It is not possible to tell whether clients with certain types of disabilities are more likely to have undetected alcohol or drug problems because of the small number of clients with some types of disabilities who participated in this study. Substantial numbers of clients in this study did have back injuries, limb impairments, and mental disorders. We can say that in each of these categories a number of clients with no TRC-identified primary or secondary disability of substance abuse or dependence were identified by the ASI and SASSI as having an alcohol or drug problem. Further investigation is needed with larger numbers of clients to determine the extent of alcohol and drug problems among clients with different types of disabilities.


Many of the study participants were quite open about their use of alcohol and other drugs. This made identification of alcohol and drug problems relatively easy. The candidness of these clients may be due to the research confidentiality protections offered to them. A study using both VR counselors and third parties (like the researchers in this study) to administer instruments could provide answers about whether clients would be as candid if services are at stake.

Perhaps the most important question in this study is the one that we are least able to answer: Do clients with undetected substance abuse have poorer VR outcomes? The question is difficult to answer, because less than half of the cases had closed. Our very tentative an-



swer so far is that clients with no substance abuse disability identified by TRC or by the researchers had the best outcomes, and that those with detected or undetected substance abuse did not do as well as clients with other disabilities.

Limitations of this study are that the sample was not randomly selected and that volunteers were used. The fact that clients are from a single geographical area and that sample size is modest are additional reasons that caution should be exercised in generalizing results. It would have been interesting to use both the ASI and SASSI with each of the study participants to determine if they produced similar results with the same clients, but time constraints made this impractical.

As far as we know, this is the first published work to determine the extent of undetected substance abuse among VR clients. Replication in other areas, especially with random samples of clients or samples stratified to provide sufficient numbers of clients with each type of disability, would be particularly useful. 

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## Notes

<sup>1</sup> Data in this paragraph were obtained from the RSA-911 Output Reporting System.

<sup>2</sup> The complete study is found in: DiNitto, D.M., & Schwab, A.J. (1991). *Substance abuse factors which interfere with entry or reentry into employment*. Austin, TX: The University of Texas at Austin, School of Social Work.

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# Adaptive Driver Training

## *a pathway to transition*

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Transportation is a persistent problem for professionals delivering transition and supported employment services to people with disabilities (D'Alonzo & Drower, 1984; The National Highway Traffic Safety Administrations 1975; Wehman, Everson, Walker, Wood, & Marchant, 1987). Special educators responsible for implementing increased school-to-community transition services find that transportation problems can grow in proportion to escalated services.

Describing the transition of youths with disabilities from school to community, Halloran (1989) noted that transition "has become a critical concern for parents, professionals, and policy makers... unfortunately, when we look back to determine what preparations have been made for students to live and work in our communities we often see a series of disjointed efforts lacking a focus on skills necessary to confront the new expectations and demands of adult life" (p. xiii). Many people with disabilities have a broad range of employment and community service opportunities because of their access to transportation. Consequently, the relationship between transition and available transportation can be inextricably entwined. A solution to the problems of transporting people who are disabled may be provided by community service agencies or benefactors. However, another solution may be to encourage people to develop automotive driving skills.

Providing transportation guidance to people who are mildly disabled may involve problems, but these problems can

be similar to the problems confronted by people who are nondisabled. However, special provisions are required when designing instruction for people who have moderate or severe cognitive, sensory, or physical disabilities.

Because of the complex and individualized character of transition programs, some transition problems may seem unavoidable. Transition is the process that enables people with disabilities to complete the learning experience

***Potential problems may be eliminated by adaptive driving equipment, techniques that compensate for physical deficits, or adaptive driver training.***

periences that are typically based and coordinated in the schools. Transition can require combined efforts of numerous people from diverse educational and community services. Transition education can commence early in the home or school and culminate with successful and productive community membership. According to Brolin and Schatzman (1989), transition for people with disabilities is a continuous, lifelong process that requires effective collaboration from a wide range of professionals. The requirement that every student with a disability receive transition services was enacted into law through the Individuals with Disabilities Education Act (IDEA) of 1990 (Pub.L. 101-476).<sup>1</sup> The following sections of this article address issues that instructors and administrators should be pre-

pared to encounter when designing a transition program that includes adaptive driver training.

### **Assessing Aptitude for Driving**

Assessing aptitude for driving an automobile can be a difficult process, especially when the potential driver has a combination of physical, perceptual, cognitive, and even emotional deficits. Special educators, physicians, therapists, rehabilitation specialists, psychologists, driver educators, and licensing agency personnel are examples of the professionals who can be consulted to evaluate the capabilities and limitations of individual driver candidates.

Driving an automobile is a complex task, requiring skills such as judgement about distance and speed, application of controlled force to brakes or an accelerator, negotiation of roadway turns, and the avoidance of hazards. Safe driving may be difficult, or even impossible, for some people with disabilities. Potential problems may be eliminated by adaptive driving equipment, techniques that compensate for physical deficits, or adaptive driver training. However, the initial stage of every adaptive driver training program should be a comprehensive assessment of aptitude for driving.

Assessing driving aptitude can be a two-part process. In an initial screening,

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**Table 1**  
**Aptitude for Driving Checklist**

	Inadequate	Adequate
1.0 Physical		
1.1 medical history	_____	_____
1.2 comprehensive physical examination	_____	_____
1.3 vision	_____	_____
1.31 acuity	_____	_____
1.32 depth	_____	_____
1.33 spatial relationships	_____	_____
1.34 figure-ground relationships	_____	_____
1.35 color blindness	_____	_____
1.36 night vision	_____	_____
1.37 glare vision	_____	_____
1.4 hearing	_____	_____
1.5 self-report	_____	_____
1.51 strength of arms and legs	_____	_____
1.52 range of motion for arms, legs, and head	_____	_____
1.53 symptoms	_____	_____
1.531 dizziness	_____	_____
1.532 weakness	_____	_____
1.533 fatigue	_____	_____
1.534 tremors	_____	_____
1.535 seizures	_____	_____
1.536 depression	_____	_____
1.537 hallucinations	_____	_____
1.54 consumption of drugs and medicine	_____	_____
1.55 use of prosthetic or orthotic devices	_____	_____
2.0 Cognitive		
2.1 attention span	_____	_____
2.2 decision making ability	_____	_____
2.3 analytical ability	_____	_____
3.0 Emotional		
3.1 unusual depression	_____	_____
3.2 unusual excitation	_____	_____
3.3 aggression	_____	_____
4.0 Legal		
4.1 driver's license eligibility status	_____	_____
4.2 driving history	_____	_____
4.3 driver education (nonadaptive)	_____	_____
4.4 driver education (adaptive)	_____	_____

one can review factors such as medical history, current physical condition, driver license status, and driver history. In a subsequent and more specialized phase of assessment, one might focus on perception, motor control, cognitive ability, driving knowledge, and the ability to operate a vehicle under simulated and actual conditions. Table 1 is a checklist of potential variables that might be the basis for a comprehensive assessment of driving aptitude.

After assessing driving aptitude for persons who are disabled, how does one determine what type of program will be responsive to the individual needs of each? Table 2, which is adapted from data contained in a report compiled by Sabo and Shipp (1988), lists several types of disabilities and select areas of potential impact for these disabilities. Table 2 contains the type of information that could complement assessments synchronized to factors such as those listed in Table 1. Individual evaluators could create a summary of this sort for the specific learners that they had assessed. This summary information could assist instructors and administrators in estimating both the feasibility and cost of an adaptive driver training program that was suited to the precise abilities and needs of their students. Such programs can incorporate adaptive driving equipment, structural modifications to vehicles, and compensatory driving techniques.

### Adaptive Driving Devices

There are many adaptive devices available commercially. These range from a simple spinner knob that can assist people who can steer with a single hand to a complex, pneumatic powered, servo assisted brake and accelerator control that can allow people with restricted ability to use their limbs. While a lack of visual acuity is sometimes corrected with lenses, blind spots, tunnel vision, or limited visual fields may require oversized and specially positioned mirrors.

All physical and perceptual deficits cannot be eliminated through adaptive devices. Severe tremors, excessive spas-

ticity, or substantial loss of visual fields are examples of deficits that can prevent persons from becoming safe drivers. Sometimes it is not augmentative devices but therapy adjustments in medication, surgical procedures, or the mastery of compensatory driving strategies that are responsible for a change in an individual's driving aptitude.

Once persons have been assessed as having the potential for safe driving, they are ready for adaptive driver training. In adaptive driver training programs, learners are advised about adaptive devices that can enhance safe operation of vehicles. Table 3 lists adaptive devices that are associated with functional handicapping conditions. Before purchasing adaptive equipment, the following guidelines should be considered. Drivers should:

- obtain an aptitude-for-driving assessment from the professional personnel at a rehabilitation or adaptive driving center;
- ask for a list of suggested adaptive driving devices and vehicle modifications from the professional personnel at a rehabilitation or adaptive driving center;
- solicit competitive bids for adaptive devices and vehicle modifications from several companies;
- consult with other drivers who have disabilities about the effectiveness of devices and modifications and about the satisfaction ratings they would assign the different companies that provide these services;
- ask personnel at a rehabilitation or adaptive driving center to check the installed devices and modified vehicle;
- request that staff at a rehabilitation or adaptive driving center ensure that devices and modifications are appropriate, accessible, and operated effectively by the driver; and
- ask personnel at a rehabilitation or adaptive driving center to recheck the equipment regularly and frequently.

The following organizations offer information and services that can assist administrators, instructors, and individuals who are involved with adaptive driver training: *American Automobile Association*, Manager—Traffic Safety,

12600 Fair Lakes Circle, Fairfax, VA 22033; American Driver and Traffic Safety Education Association, 123 North Pitt Street, Suite 509, Alexandria, VA 22314; American Medical Association Physicians' Guide for Determining Driver Limitation, 535 North Dearborn, Chicago, IL 60610; Association of Driver Educators for the Disabled, ADED Secretariat, 33736 La Crosse, Westland, MI 48185; Chrysler Motors—Physically-Challenged Resource Center, P.O. Box 159, Detroit, MI 48288-0150; Easter Seal Society for Crippled Children & Adults, Inc. Education for the Handicapped Person Project, 37 Harvard St., Worcester, MA 01608; Louisiana Tech University—Adaptive Driving Program, Center for Rehabilitation Science and Biomedical Engineering, P.O. Box 10426, Ruston, LA 71272; Rehabilitation Engineering Society of North America, 1101 Connecticut Ave., NW, Washington, DC 20036; U.S. Department of Transportation—Handicapped Driver Section, 400 Seventh Street, SW, Washington, DC 20591; and Veterans Administration—Prosthetic and Sensory Aids Service, 810 Vermont Ave., NW, Washington, DC 20420.

The authors gratefully acknowledge the extensive information that was provided by Steven Sabo and Michael Shipp through the Louisiana Tech Center for Rehabilitation Science and Biomedical Engineering.

## Notes

<sup>1</sup> This law defines transition services as "... a coordinated set of activities for a student, designed within an outcome-oriented process, which promotes movement from school to postschool activities, including postsecondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation. The coordinated set of activities shall be based upon the individual student's needs, taking into account the student's preferences and interests and shall include instruction, community experiences, the development of employment

Table 2						
Impact of Disabilities on Selective Aspects of Driving						
Type of Disability	Arm Control	Leg Control	Reaction Time	Entry & Access	Driver Position	Perception
Amputation	◆	◆	◆	❖	❖	❖
Cerebral Palsy (mild)	◆	◆	◆	●	●	❖
Emotional Disorder	❖	❖	◆	❖	❖	◆
Friedreich Ataxia	◆	◆	◆	●	●	❖
Hearing Impairment	❖	❖	◆	❖	❖	◆
Learning Disability	❖	❖	◆	❖	❖	◆
Mental Retardation (mild)	❖	❖	◆	❖	❖	◆
Muscular Dystrophy (mild)	◆	◆	◆	◆	◆	◆
Multiple Sclerosis (mild)	◆	◆	◆	◆	◆	◆
Spina Bifida	◆	●	◆	●	●	❖
Spinal Cord Injury	●	●	◆	●	●	❖
Traumatic Brain Injury	❖	❖	◆	❖	◆	◆
❖ = impact tends to be minimal ◆ = impact tends to be moderate ● = impact tends to be severe						

Table 3	
Adaptive Devices to Assist Drivers with Disabilities	
Problem	Adaptive Devices
Vehicle Entry	automatic door opener, platform lift, rotary lift, cartop wheelchair carrier, lowered floor, raised roof
Steering	steering column extension, horizontal steering system, foot control steering, spinner knob, pin steering system, prosthesis compatible steering wheel
Accelerator and Brake Access	hand controls, left foot accelerator, reduced effort brakes, electrical parking brake
Switch and Control Access	electric driving consoles, elbow switches, right hand turn signal lever, left hand gear selection lever
Driver Position	power seats, adjustable steering wheel, power pan, detachable seats, wheelchair lock downs

and other post-school adult living objectives, and, when appropriate, acquisition of daily living skills and functional vocational evaluation." (29 U.S.C. §1401(a)(19) (Supp. 1993).

## References

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from school to work for persons with disabilities (pp. 1-21). NY: Longman.

2. D'Alonzo, B.J., & Drower, I. (1984). Driver education for the mildly handicapped: One approach. *Teaching Exceptional Children*, 17 (1), 10-17.

3. Halloran, W. (1989). Foreword. In D.E. Berkell & J.M. Brown (Eds.), *Transition from school to work for persons*  
Continued on page 37



# Careers in Rehabilitation

## *with an undergraduate degree in rehabilitation*

Tom Evenson, Ph.D.  
Celia Williamson, Ph.D.

A bachelor's degree in rehabilitation provides the foundation for a myriad of careers within the broad spectrum of human services. The purpose of this article, which is based on the National Council on Rehabilitation Education's (NCRE) position statement on Undergraduate Education (1987), is to provide specific information about some of those career options.

### Undergraduate Education

NCRE's position statement on Undergraduate Rehabilitation Education stresses that the foundation of a quality baccalaureate program is its emphasis in preparation in the liberal arts. Coupled with focused pre-professional training in rehabilitation, the liberal arts component prepares students to become "thinkers" as well as "doers" within their careers. According to NCRE, the objective is to graduate people who are knowledgeable and literate in the humanities and who have competencies in the social and psychological sciences as they pertain to people with social, physical, mental, or emotional disabilities. The primary purposes of the undergraduate programs are to prepare students for direct employment in rehabilitation-related positions and/or graduate work in rehabilitation or allied human service professions.

Undergraduate programs in rehabilitation are typically associated with programs in rehabilitation, counseling, psychology, allied health, education, or social work. While there may be variance in their specific degree requirements, typi-

cal course work or content, in addition to course work in the liberal arts and sciences, most programs include:

- the history and philosophy of vocational rehabilitation and independent living programs;
- human growth and development;
- legal and ethical principles;
- case management;
- interpersonal helping and human relations;
- interviewing;
- community resources;
- client advocacy;
- behavior management;
- introductory sections on job development and placement, vocational evaluation, supported employment, and medical and psychosocial aspects of disability; and
- practicum/internship experience in a rehabilitation service setting.

In some cases, undergraduate programs may offer specialization tracks within the general rehabilitation curriculum. Examples of specialty areas include vocational evaluation, deafness, substance abuse/addiction studies, mobility training, and criminal justice. Students will frequently supplement their major in rehabilitation services by selecting a minor in such allied areas as psychology, social work, sociology, criminal justice, communication disorders, recreation, or business administration.

### Career Possibilities for Graduates in Rehabilitation Services

*Job Titles.* While there may be significant overlap in job responsibilities, job

titles for rehabilitation majors tend to vary depending on the place of employment. Examples of job titles include rehabilitation specialist, interviewer, placement specialist, job developer, personal-social adjustment instructor, caseworker, supported employment specialist, job coach, counselor aide, vocational evaluator aide, mental health technician, independent living coordinator, corrections specialist (parole/probation), client advocate, eligibility worker, and public health technician.

*Job Competencies.* Competencies required by persons in these types of positions also vary with the primary focus of the job setting. However, at a minimum, rehabilitation graduates can be expected to bring the following kinds of knowledge and skills to any position: intake interviewing, case finding and community outreach, basic case management, fundamental vocational evaluation and work adjustment techniques and procedures, preliminary job development and job placement techniques, client advocacy, individual rehabilitation program planning, behavior change techniques, and specialized administrative/supervisory skills.

*Employment Settings.* Because the baccalaureate is designed to prepare students as generalists within the rehabilitation field, graduates from these programs are qualified for a variety of entry-level positions in human services. Employers select these graduates because of their strong orientation in rehabilitation philosophy with its positive emphasis on abilities and potential. They are trained to take a holistic approach aimed at maximizing the quality of life of each person with whom they work.

Baccalaureate-level rehabilitation majors can be found in virtually any type of



agency or program that provides services to people. The most frequent employment settings are those directly related to rehabilitation, such as work adjustment programs, supported employment programs, sheltered workshops, group homes, centers for independent living, mental health centers, developmental disabilities programs, disability specific programs (blind, deaf, head injured, etc.), client assistance programs, state vocational rehabilitation agencies, proprietary rehabilitation services, and disability determination units.

Because their specialty is working with people, rehabilitation majors are qualified for the same types of employment as graduates of psychology, social work, sociology, and similar programs. Therefore, a significant number of rehabilitation graduates are employed in rehabilitation-related agencies and programs, such as hospitals, employee-assistance programs, correctional programs (institutions, probation, and parole), senior centers and nursing homes, substance abuse programs, therapeutic recreation services, public volunteer programs, disabled student services programs, and human resource development in private industry. The rehabilitation philosophy and its basic concepts provide a constructive addition to the traditional approaches used in many of these settings.

*Graduate Study.* Because the professional degree in the field of human services is the master's degree, many students use the baccalaureate in rehabilitation as a bridge to their ultimate professional goals. While rehabilitation counseling is the most common professional specialization selected by undergraduate majors, many students pursue graduate work in the rehabilitation specialties of vocational evaluation, work adjustment, rehabilitation administration, job placement, and supported employment. Other students use the undergraduate rehabilitation degree as a foundation for graduate study in ancillary professional areas. It is not uncommon, for example, for students to pursue graduate degrees in social work, physical therapy, occupational therapy, psychology, special

education, counseling and guidance, public administration, or business. Students find that their undergraduate training in rehabilitation services provides them with important dimensions that significantly broaden their ability to work with people in almost any type of human service area.

Graduates of bachelor's degree programs may be the best spokespersons for the relevance of the degree to their own careers.

The following is a narrative by a 1978 graduate of the undergraduate program at the Center for Rehabilitation:

***One 1990 graduate indicated that he had received six job offers during his final semester in the program.***

"I began work on the Monday after graduation as an Extended Rehabilitation Services Counselor at a local Goodwill. The supervisor stated that she hired me because my degree was perfect for the job. She was particularly impressed that I knew how to write Individual Program Plans, understood different types of disabilities, and knew basic behavior analysis techniques. Within 1 year I became the coordinator of the program.

"I was later recruited by the local Association for Retarded Citizens to establish a work-activity center for their clients, then moved to the MHMR center where a new psychosocial rehabilitation program was being developed. Persons interviewing me stated my knowledge of rehabilitation principles, individual treatment planning processes, structured learning theory, and behavior analysis convinced them to hire me. They were impressed with rehabilitation's focus on the wellness rather than the illness of the individual, a philoso-

phy they endorsed. I was promoted to coordinator of the program within 5 months. Within 2 years I was promoted again, to residential coordinator, while maintaining my responsibilities with the psychosocial rehabilitation program. Two years after that, I was promoted to the position of director of mental health services. At this point, I still had only my bachelor's degree, but had entered into a master's program.

"What I liked most about the undergraduate rehabilitation program was its applied components. The program taught me how to make decisions and problem solve, as well as how to carry out specific interventions. I learned how to write a task analysis, how to write and implement training plans, and how to manage a caseload. These specific skills were given foundation and context through an indoctrination into the theories and philosophy behind rehabilitation. This mix of practical and philosophical information is critical, because, as the old saying goes, the answers are not in the back of the book. In the complex world of human service delivery, you need to know what to do, how to do it, and in order to innovate, you need to know why it is being done at all."

The stories of the applicability of the degree are repeated in other contexts by other graduates:

- One 1990 graduate indicated that he had received six job offers during his final semester in the program. He took a job which focused on job analysis and accommodation design. One year later, the company had promoted him, moved him to another city, and was helping to finance his graduate work so that he could move into the ranks of management.

- A 1991 Hispanic graduate quickly found a position in the state VR agency

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providing bi-lingual and culturally focused services to their clientele.

- Another graduate spoke of the impact of the philosophical content: "The undergraduate program in rehabilitation raised my consciousness about the impact of disability and ingrained in me the importance of taking a holistic approach rather than focusing on the disability.

"As a probation officer for persons with emotional and cognitive impairments, I find myself in a system which tends to focus on the offense. Yet, when I consider people and their needs first, I am more able to assist in their rehabilitation and prevent incarceration."

Bachelor's degree programs are capable of producing graduates who are grounded in a philosophy of client em-

powerment and equipped with initial knowledge and skills to enter into human service delivery. Through their education, these new providers are given the tools to continually increase their knowledge and skill base. Thus, an undergraduate degree in rehabilitation provides both a platform for service and a stepping stone to higher professional levels of human service delivery.

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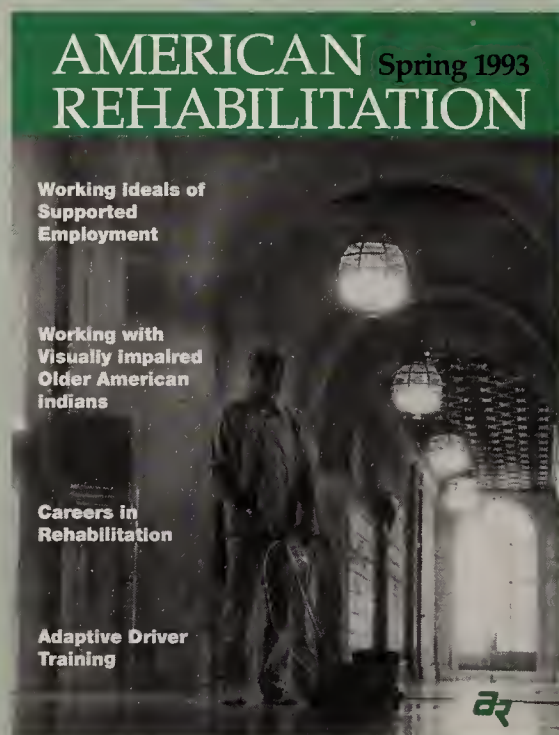
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## Notes

<sup>1</sup> This partial list was compiled as a part of a review of undergraduate rehabilitation programs now being conducted at the request of NCRE, in cooperation with RSA and CSAVR. The initial report of findings was presented at the 1993 NCRE/RSA/CSAVR Conference in Washington, DC. 

## References

National Council on Rehabilitation Education Committee on Undergraduate Education. (1987). NCRE position statement on undergraduate rehabilitation education. *Rehabilitation Education*. 1(1) 19-27.



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# Supported Employment



*Many Job Path Trainees work in food services in corporate cafeterias.*

## Working Ideals

*Mark Usdane*

These are exciting times, with many opportunities to help shape services for people with severe disabilities. A glance backward reveals many advances over the past 20 years. The custodial emphasis of huge, impersonal institutions has given way to goal-oriented community-based services rooted in the individual needs of people with disabilities. More recently, mainstream employment programs have pressed the system's boundaries out still further by demonstrating, over and over again, that people with severe disabilities can work in the conventional labor market, as long as they have access to the right combination of training and support. The idea and techniques of supported employment, just like those of the community residential move-

ment, have earned the confidence of consumers and providers alike as a means of increasing the self-sufficiency of people with disabilities. Along the way, supported employment has altered the day service and vocational rehabilitation landscape.

### **Shrinking Boundaries and Promoting Choice**

Two fundamental, interwoven trends lie at the heart of the progress over the last two decades. The first is a change in perception and attitude, characterized by reduced and less rigid boundaries between the world of people with disabilities and the world of everyone else.

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*Mr. Usdane is Associate Director, Vera Institute of Justice, New York, NY.*



Before deinstitutionalization, the border between these worlds was sharply delineated. People with severe disabilities were viewed as abnormal rather than normal, and their residential asylums bore no resemblance to places where nondisabled people lived. Today, these boundaries are significantly less immutable, thanks to the rise of residences and services in the community. Supported employment programs help this cause by blurring the boundaries between disabled and nondisabled people in the workplace.

The second trend emphasizes choice and flexibility for people with disabilities. While still an elusive goal in practical terms, the conviction that individuals themselves should have choice concerning what services they receive has become central to ideas about program development. Too often, options continue to be presented in paternalistic terms. The implicit message is that individuals with disabilities are not fully capable of bearing responsibility. Service providers need to continue moving away from infantilizing clients and toward insisting on a genuine involvement of people with disabilities in decisions about which services fit their needs. In order to offer real choice, the system of services must be flexible enough to accommodate a wide variety of options and creative enough to serve people with a broad range of disabilities. There has been progress in this area, but we have a long way to go.

Optimism that both these trends—inclusion and self-determination—will continue is not unwarranted. In fact, it seems possible that past changes will pale in comparison to shifts to come by the end of this century. And although the pace of that change remains in doubt, a question Tom Bellamy raised some years ago in his seminal work, *Supported Employment*, has now been answered: It is no longer too early to tell if supported employment, with its emphasis on flexibility and choice, will be a mere fad or whether it will constitute fundamental change. Supported employment, and its working ideals, have taken root all around the country.

## Keeping Services Headed in the Right Direction

The breaking down of unnecessary, often counterproductive, boundaries that permeate the system needs to continue. Today, for example, there are rigid distinctions between employers, service recipients, and service providers. Their respective roles need to be woven together. Some employers have already become sufficiently convinced of the benefits of supported employment to find ways to train and support workers with disabilities just as they train and support workers without disabilities—using corporate resources.

***Ideally, the rehabilitation agency's move into an advisory role would not be limited to employment issues.***

The training of workers with disabilities becomes, in that way, an activity incorporated within the basic business operations of companies. Companies are also learning to harness the natural inclination of established workers to aid in the seasoning of all new employees, a process that in many ways exemplifies the desired interaction between job coach and trainee. Some companies are capitalizing on this innate organizational capacity to carry out training, supplemented by their own job coaches. Once an employer has accepted the utility of hiring workers with disabilities, it is not as big a leap as it might seem to go from using a supported employment provider to conducting the necessary training in-house with a company's own employees.

How would such change affect the role of the rehabilitation agency? Obviously, its training component could be substantially reduced. It is possible to envision compact, agile, streamlined agencies in the not very distant future, capa-

ble of providing concentrated, immediate expertise to employers on a consulting basis. They would be something like present Employment Assistance Programs (EAP's) in offering short-term consultation and intervention to help people get and keep jobs. They would not be nearly as elaborate as they are now. Their agenda could be relatively limited. Less might turn out to be more.

## Tackling Residential Reform

Ideally, the rehabilitation agency's move into an advisory role would not be limited to employment issues. Rehabilitation agencies might increasingly take on the task of facilitating a parallel movement toward self-sufficiency and integration in the lives of people with disabilities outside the workplace. In the years since the mid-seventies, many states have seen community-based group homes substantially replace institutional living. For many who inhabit them, these community residences could serve as stepping stones to an apartment and greater self-sufficiency, but the special support that residents need to make a successful transition to more independent living is not at hand. Rehabilitation agencies are well-equipped and well-positioned to press for and support change in the total lifestyles of clients who seek their help. The principles that presently underlie shifts of people from segregated day service programs to mainstream work could guide their movement from group homes to greater independence in supervised apartments.

Over the past 20 years or so, the way government spends money on people with severe disabilities has changed dramatically; and, on the face of it, the changes also look thorough and comprehensive, integrating reforms in patterns of residential care with shifts, like supported employment, in the aims of day services. After all, places like New York State's notorious Willowbrook have been closed, its more than 5,000 former residents scattered to group homes around the neighborhoods of New York City. Over the same period, programs like Vera's Job Path, a transi-



tional and supported employment project for people with developmental disabilities, have helped thousands of people cross over from day centers and sheltered workshops to real jobs in the conventional labor market.

In New York State alone, hundreds of group homes now house thousands of adults with severe disabilities who used to live at Willowbrook or places like it. By and large, these homes are clean, well-supervised, nice places to spend time in. Mostly run by voluntary agencies, these homes provide a life that is about as different from ward life in a state institution as it can get. Treatment plans, client goals, and progress notes underscore the noncustodial nature of work at hand. But almost no one asks, in a fundamental and systematic way, if any of the people with disabilities who have crossed the gap from institutions to group homes could take the next step and establish themselves in, say, an apartment in a neighborhood and with roommates (or not) of their own choice. It is possible that this question cannot get officially posed until a plausible program—or array of supports—comes into view that can help people cross the gap between congregate living and a home that is more their own. People who have puzzled out how to make supported employment work have a headstart on inventing that new housing service.

## Trading in the Continuum

For progress to continue, boundaries must be reduced precisely where maximum fluidity was originally envisioned—along the institution/day treatment/workshop/employment continuum. The present system was designed on a flow-through model, with the idea that people who are disabled would, wherever possible, progress from one level to the next, all the while gaining skills and self-sufficiency. In practical terms, this is almost wholly unrealized. For many people with disabilities, these theoretical steps along a continuum have led to a dead end, with little hope of their moving out of them. In New York State, less than 1 percent of the over

14,000 people in day treatment have “graduated” to workshops or competitive employment. Workshops, furthermore, have tended to focus on intramural productivity, rather than training for full-time competitive employment on the outside. Even supported employment programs have not carried out the mission they originally adopted: rather than providing services to the most severely disabled people, usually those who are now either targeted for day treatment or already there, these programs have dealt predominately with more capable people whose employment and training needs might more

*Supported employment seeks to turn conventional program development upside down, putting client needs and aspirations first and making program design a consequence of that assessment.*

readily be fitted to a transitional employment or direct placement service.

Still, there has been a lot of progress. Although no one seems to have a practical plan to help clients who are in day treatment move along the continuum, funds specifically earmarked for moving people with severe disabilities out of workshops are now more readily available. These initiatives have heightened the day-to-day sensitivity of program managers to their clients' employment potential. And these shifts in attitude have led many facilities to implement their own supported work components. But it is still too often the prevailing belief within these programs that the majority of their enrollees are unsuitable for outside employment. As evidence to the contrary mounts, however, this attitudinal barrier to wide-

spread adoption of supported employment techniques will shrink.

Over time, supported employment ought to become an outcome in the first case, a place where people begin. It is notoriously difficult to move people from one place, where they are reasonably comfortable, to another place, fraught with unknowns. Yet, that is a central feature of the continuum concept.

## Overcoming Obstacles: Money and Management

Boundaries persist, in no small measure, because public funding has a hard time keeping up with the elastic needs of people; too often, individual needs are batch-processed by service systems unwilling to be imaginative about idiosyncratic solutions. It is still almost universally the case that funding sources tend not to reflect the wide variety of needs within the system. Instead, they maintain extremely specific eligibility requirements which suggest that service needs are open to neat sorting out into one of a handful of program types. Such boundaries can easily lead to decisions that people with disabilities are ineligible for this or that service, creating widespread potential for people to fall through cracks and receive services that are poorly suited to their needs or, worse, no services at all.

Supported employment seeks to turn conventional program development upside down, putting client needs and aspirations first and making program design a consequence of that assessment. In theory, there are as many choices within a supported employment program as there are clients. The old model of day service had two or three program types; the client was fitted into the one that provided the closest mesh between individual needs and the capacity of a given service to respond to those needs. In supported employment, the client receives whatever level of service he or she requires. This eliminates mismatches created by best efforts to meet needs within the structure of pre-existing service models like sheltered workshops or day treatment programs.



The theory of customized services still meets an unhappy end in day-to-day terms. For example, some funding sources, like present incarnations of Federal Job Training Partnership Act authorizations, continue to emphasize fast work, rapid-fire placements, and time-limited support. Such a model neglects the essence of supported employment, with its concept of individually tailored supports whose intensity and duration are grounded in an assessment of whatever help an individual client needs to get and keep a job in the regular workplace.


Another barrier to the widespread implementation of supported employment is that its funding sources are not as stable as its primary alternatives. For example, the fact that Medicaid is a reliable and steady source of funds for day treatment attendees acts as a disincentive to movement out of these programs. Funding sources such as Medicaid—however essential to the widespread development of community-based programs for people with the deepest disabilities—have tilted the system toward intensive service models which can be unnecessarily expensive and much less likely to foster self-sufficiency than community-based employment models. Some of the best thinking about future financing has occurred within discussions about what form a national Medicaid waiver program ought to take. In a state like New York, where an addiction to Medicaid has had more than a decade to get a hold on state officials and service providers alike, relief for the use of these dollars for employment services is essential.

## Keeping an Eye on the Prize

It is precisely because it is so boundary-free, flexible, and rooted in choice that supported employment needs to continue growing as an option for people with disabilities; and, although the building of consensus around supported employment is already well underway, the essence of the concept makes this process difficult. What is best about the supported employment design—its attempt to be malleable enough to meet a

wide variety of individual needs—is exactly what makes it difficult to describe well. Its techniques defy pigeon-holing, and are thus resistant to conventional bureaucratic efforts to define them. In many ways, the program model is still being invented. No matter what anyone says, all the forms its techniques will ultimately take are not yet known. This is largely because we do not yet know all the different kinds of individuals who will be best served in supported employment. And it is perhaps time to give up our allegiance to “programs” and “models,” respecting instead the unique gifts, dreams, and needs of each person with a disability.

People with disabilities are not the only ones who stand to benefit from greater choice and fewer boundaries within the system. The more this population is mainstreamed, the more people without disabilities interact with them on a regular basis in settings where differences between them are de-emphasized. This can only raise the consciousness of society at large for a significant minority in the most positive of ways. It is not being overly simplistic or naive to suggest that when this happens everyone gains.

The commitment to integration needs constant reaffirmation. It is still easier than it ought to be to slip back into thinking and operating with unnecessary boundaries—boundaries between people with disabilities and people without them, between employment services and employers, between service providers and advocates, and, finally, between people who receive services and people who govern services. At their often elusive best, supported employment techniques can give us a standard for an approach that puts inclusion and self-determination for people with severe disabilities ahead of any other goals. 

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# Rehabilitation in Vermont

*Raymond L. Milhous, M.D.*

Vermont is a special place. Rolling hills, lakes, dairy farms, picturesque villages. Hiking, skiing, boating. Six hundred thousand people who have enough space to breathe, yet are close enough to care. Uncluttered, no billboards, little trash. The Green Mountain State.

Vermonters are special people, with a strong work ethic. They are proud of their heritage, proud of their independence, and unpretentious, conservative, generous. They have strong family ties and guard their privacy and quality of life.

Many are also disabled and many are poor. Dairy farming means long hours for minimal returns and machines that cause injuries. Many elderly have come here, or have stayed here, and have experienced the impairments that come with age. Throughout these green mountains are people who need rehabilitation.

Rehabilitation in Vermont. Is it also special? Does the mystique of Vermont influence the rehabilitation process? Are things different here than in the larger, more populous states?

To answer these questions we need to describe Vermont's rehabilitation programs and how they work together.

## The Consumer Movement

Rehabilitation properly begins with the consumers of rehabilitation services. Consumers in Vermont have long played a central part in the rehabilitation process. Since the early 1960's, the state rehabilitation agency has supported their involvement in the rehabilitation process—not only in the de-

velopment of the individualized written rehabilitation program but also in agency policy issues. People with disabilities were recruited for administrative and staff positions, consumer advisory boards were formed and advocacy groups encouraged.

Among the advocacy groups, the Vermont Center for Independent Living (VCIL) is foremost, representing a wide cross-section of disabilities. Managed and staffed by people with disabilities, this group provides peer counselling, advocacy programs, consultation regarding architectural barrier removal, assistive technology information, and help for people to live more independently. Peer counselors are located strategically throughout the state.

Other consumer oriented groups actively support the needs of people with specific impairments: traumatic brain injury, cerebral palsy, multiple sclerosis, heart disease, and visual, hearing, and psychologic impairments. Each serves its specific constituents and in our small state actually work together for the common good of all people with disabilities.

Another group, "The Physically Challenged Families of Rural Vermont," consisting of farmers with disabilities and their families, provides support for farm families coping with the special problems of farming with a physical impairment.

Each consumer group has made its mark by working closely and meaningfully with governmental and private rehabilitation programs and with people with disabilities to improve services in Vermont.

Vocational Rehabilitation in Vermont has had, through the years, a consistent commitment to first serve people with substantial disabilities. It is strongly

committed to being responsive to the consumers of its services. In its deaf program, for instance, three of five counselors are themselves deaf, as is the State Coordinator of Services for the Deaf and Hard of Hearing. It contracts with VCIL to manage its independent living programs.

Innovation and linkage has been the hallmark of Vermont's VR program. In 1956, long before other states were considering this, Vermont established half-way houses to allow people from the state hospital to reenter their communities. This first, which has now been duplicated in many states, resulted over time in the reduction in population of the state hospital from 1,300 to about 100 people today.

The VR agency established and administered the state's first medical rehabilitation facility in the 1960's. It also supported an innovative program to educate local health care workers and counsellors to provide rehabilitation for people with spinal cord injuries in their homes. In addition, it developed a statewide industrial home work program where isolated Vermonters with disabilities were brought work to do in their homes. This program, started in the 1950's, is still operational today.

For the past 10 years, vocational rehabilitation has routinely utilized supported employment and onsite trainers.

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*Dr. Milhous is Medical Director of the Rehabilitation Center at the Medical Center Hospital of Vermont in Burlington, Professor and Chairman of Rehabilitation Medicine at the University of Vermont College of Medicine, and Chief Medical Consultant of Vermont's Division of Vocational Rehabilitation.*



It sponsors a program for Vietnam veterans in cooperation with the Department of Employment and Training. It has close working relationships with Medicaid, Social Security, Handicapped Children, Mental Health, the Head Injury Association, and the University's Rehabilitation Medicine program. In 1989, it merged with the State Office on Aging, allowing for a continuity of rehabilitation services throughout one's lifespan.

Working out of four regional offices, VR counsellors are truly "on the road." It is not unusual for a counsellor to spend 2-3 days per week visiting clients in remote corners of Vermont's "Northeast Kingdom" or at the end of dirt roads in southern Vermont. Rehabilitation plans are individually developed for everyone — there are no tailor-made programs or facilities to which clients may be referred.

Two other innovations stand out: the Rural and Farm Family VR Program and "VABIR," the Vermont Association of Business, Industry and Rehabilitation. "Farm Family," established in 1969, unites VR with the University of Vermont Extension Service. Rehabilitation counsellors work along side their Extension Service colleagues to keep disabled farmers and their families on the farm. Approximately 50 percent of referrals come from extension workers and in about 75 percent of these the rehabilitation plan is developed jointly between the VR counsellor, the extension agent, and the client and his or her family.

VABIR works with business and industry leaders to help them rehabilitate and accommodate to the needs of their injured workers. Located in each VR regional office, VABIR representatives assist counsellors with their rehabilitation plans and also contract directly with private insurers and industries to expedite return-to-work as soon as possible after a worker is injured.

## Medical Rehabilitation

Three inpatient rehabilitation centers serve the people of Vermont: a 40-bed center at the Medical Center Hos-

pital of Vermont (MCHV) at the University of Vermont in Burlington, a 10-bed program at Mount Ascutney Hospital in Windsor, and a 12-bed program at the Rutland Regional Medical Center in Rutland.

The Rehabilitation Center at MCHV offers well-developed sub-specialty rehabilitation programs for people with spinal cord and brain injury, stroke, amputation, and neurologic, orthopaedic, cardiac, and respiratory impairments. The center was established in the early 1960's by the Vermont Division of Vocational Rehabilitation and has been active in training medical, nursing, physical therapy, occupational therapy, and medical psychology students in the practice of rehabilitation. It attracts patients not only from all of Vermont, but also from the northeast section of New York as far west as Lake Ontario. Its medical director also serves as chief medical consultant for the state VR program.

The Mount Ascutney Hospital Rehabilitation Unit serves the Connecticut River Valley and is affiliated with Dartmouth Medical Center in Hanover, New Hampshire. It is a dynamic program in a truly rural setting. The Rutland Regional Medical Center's Rehabilitation Unit—newest of the three centers—provides state-of-the-art rehabilitation for people in the southwest and central portions of the state.

The directors of the three centers meet regularly to coordinate efforts and assure the best service for all Vermonters.

## Children's Rehabilitation

The Vermont Achievement Center in Rutland has long been the state's leader in children's rehabilitation. It combines special education for children who have multiple physical handicaps with outpatient and inpatient therapy programs and has outreach programs into all of Vermont. It works closely with the Program for Children with Special Health Needs of the State of Vermont which coordinates outpatient rehabilitation services for Vermont's children.

The University of Vermont's Special Education Department, which is also

active in children's rehabilitation, provides interdisciplinary consultation to schools throughout Vermont for children with disabilities.

Two Vermont projects funded by the National Institute on Disability and Rehabilitation Research (NIDRR) should be mentioned.

The Rehabilitation Engineering Center at the University of Vermont, funded by NIDRR since 1983, focuses on research into the prevention, treatment, and rehabilitation of people with "the silent disability," low back pain. Its clinical affiliate (not federally funded), the Spine Institute of New England (SPINE), provides comprehensive diagnostic, treatment, and rehabilitation services for people suffering from low back pain.

Vermont's Assistive Technology Program, also funded by NIDRR, integrates the efforts of a number of state, voluntary, and private rehabilitation providers to bring advances in technology to Vermonters with disabilities.

## Summary

So, is rehabilitation in Vermont any different from elsewhere? Most states have strong vocational rehabilitation programs, medical rehabilitation centers, and consumer advocacy. What is different about working in a small rural state?

First, there is easy communication. It is still possible in Vermont for any citizen to call people at all echelons of state government, including the governor, and get results. People in rehabilitation know one another on a first name basis. Communication among VR, Social Security Disability, Medicaid, and other state agencies occurs daily. People in various rehabilitation programs trust each other, and they know that progress is best made when all components of the rehabilitation process cooperate.

A second fact that makes Vermont different is the rural mindset that work is important and that families are important. People with disabilities want to stay in their communities and with

*Continued on page 37*



# NEW PUBLICATIONS AND FILMS

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## **Friendships and Community Connections between People with and without Developmental Disabilities.**

Angela Novak Amado, editor. Paul H. Brookes Publishing Co., Inc., P.O. Box 10624, Baltimore, MD 21285-0624. 368 pages. Softcover, \$29.

Contributions from 21 authors with varied experiences in advocacy, service provision, parenting, support services, and research attempt to shed light on how to facilitate friendships among people with and without disabilities. Each author, from his or her own unique perspective, examines a different facet of friendship, such as recent lessons learned during the last several years of friendship building; work and leisure relationships; community associations and groups; gender-related expectations; religious considerations; the role of love, affection, intimacy, and sexuality; and innovative programs around the country that nurture friendships.

## **Personal Construct Psychology in Clinical Practice: Theory, Research and Applications.**

David A. Winter. Routledge, Chapman & Hall, 29 West 35th Street, New York, NY 10001. 464 pages. Hardcover, \$85, U.S.; \$106, Canada.

Based on the theory introduced in 1955 by George Kelly, this book is a comprehensive account of the clinical applications of personal construct theory. In this one volume, the author brings together theoretical analyses, research findings, and descriptions of diagnostic and therapeutic approaches, amply illustrated with case material, in relation to a wide range of clinical problems.

## **Public Mental Health Marketing: Developing a Consumer Attitude.**

Donald R. Self, DBA, editor. The Haworth Press, Inc., 10 Alice St., Binghamton, NY 13904-1580. 214 pages. Hardcover, \$32.95.

A compilation of current knowledge in public health marketing, this volume was designed to help practitioners and researchers learn to target specific groups more effectively, thereby increasing their marketing effectiveness to benefit both mental health agencies and the people they serve. It presents a cross section of recent research on the many participants in the mental health system, including clients, donors, internal stakeholders, and the general public.

This book contains original research, tutorials, and case studies in areas such as the public as a target market, primary and secondary resource markets, adolescents as a prevention and intervention market, and promotional and evaluative tools.

## **Manual of Orthopaedic Surgery for Spasticity.**

Mary Ann E. Keenan, M.D., Scott H. Kozin, M.D., and Anthony C. Berlet, M.D. Raven Press, 1185 Avenue of the Americas, New York, NY 10036. 176 pages. Hardcover, \$75.

This book was written to provide the orthopaedic surgeon with a systematic guide to the surgical correction of spastic limb deformities. This is an operative manual intended to serve as a clearly illustrated guide to complex patients with neurologic problems that result in limb deformities. The techniques are applicable to persons with varied causes of spasticity. Each procedure follows the same format and presents the clinical problem, the rationale for surgery, the

operative technique, and postoperative care. The information contained in this manual should also be useful to all professionals involved in the care of people with neurologic impairments.

## **The Problem Solvers: People with Disabilities in Engineering Careers.**

Beth Goodrich and Virginia Stern, editors. American Association for the Advancement of Science (AAAS), P.O. Box 753, Waldorf, MD 20604. 26-minute videotape. \$20 each plus \$4 postage and handling for each order.

Produced by Lucy Jones, The Video Difference, Inc., 134 Oliver Ave., Pittsburgh, PA 15202, this video presents a convincing and inspirational documentary about people with disabilities who are engineering students and professionals. Featured are 24 people with disabilities who study and work in various fields of engineering, including electrical, civil, chemical, electronic, environmental, mechanical, materials science, and computer science. They represent different age groups, varied ethnic and racial backgrounds, different parts of the country, and a variety of disabilities. Their common bond is the desire to excel in the field of engineering. They describe their challenges, which include physical barriers, communication difficulties, and attitudinal roadblocks, and reveal how their lives were shaped by the major themes that are featured in the video—assistive technology, choosing engineering as a profession, creating an empowering environment, friends and family, attitudes, invisible disabilities, on-campus support, real-world experience, the Americans with Disabilities Act, self-reliance, and career and other opportunities in engineering.



**Madness and Social Representations: Living with the Mad in One French Community.**

Denise Jodelet. *University of California Press, 2120 Berkeley Way, Berkeley, CA 94720 and 50 E. 42nd St., R. 513, New York, NY 10017. 316 pages. Hardcover, \$49.*

In this book, the author probes society's conception of "madness" through a study of the small French community of Ainay-le Château, where a colony for people with mental illness has been established since 1900 in which the patients are not enclosed within an institution but live with ordinary families in the community. The author focuses on a number of fundamental themes: the nature of identity, the relation of representation to action, and the notion of social memory.

**You're Not Alone.**

John Sabolich, CPO. *Sabolich Prosthetic & Research Center, 1017 N.W. 10th Street, P.O. Box 60509, Oklahoma City, Oklahoma 73146. Toll free telephone: 1-800-522-4428. 356 pages. Softcover, \$7.95 plus postage and tax.*

A compendium of prosthetic information accompanied by a collection of personal stories from 38 amputees who share their feelings and experiences, this book is designed to provide basic information for amputees, their friends and families, and those who may be facing an operation to remove a limb. Those who share their stories are candid about the physical and emotional pain of amputation, grief over losing an arm or leg, frustrations and triumphs with a prosthesis, and the courage it takes to put pity aside and go on with life.

**When Your Child Goes to School After an Injury.**

Marilyn Lash. *Exceptional Parent, 1170 Commonwealth Avenue, Boston, MA 02134-4646. 72 pages. Softcover. One copy, \$7.50. Ten copies, \$52.00. Twenty copies, \$90. Fifty copies, \$190. One hundred copies, \$325.*

One of a series of guides for families on the effects of childhood injuries, this book was developed by the Research

and Training Center on Rehabilitation and Childhood Trauma, Tufts College, Boston, MA. Returning to school with new needs for education and physical assistance raises many questions and concerns for children, parents, classmates, siblings, and teachers. Applying for special education and related services is complicated by the need to coordinate communication between hospitals, specialists, schools, and families. Many practical, detailed suggestions and lists are included plus special chapters on the effects of traumatic brain injuries on children's ability to learn, the use of special communication systems, and safe transportation for children with disabilities. A description of federal laws relevant to children with disabilities is given with tips on finding local services.

The series was produced in response to the frustrated search by many families for guidance and practical information as they struggle to cope with and recover from the emotional, physical, and financial aftermath of childhood injuries.

**New Technologies and the Employment of Disabled Persons.**

H. Allan Hunt and Monroe Berkowitz, editors. *ILO Publications, International Labour Office, ILO Publications Centre, 49 Sheridan Ave., Albany, NY 12210. 162 pages. Softcover, \$16 plus \$3 postage and handling.*

This is an international report on the second phase of a project conducted by Rehabilitation International and sponsored by the International Labour Office of Switzerland. This report focuses on four themes: new technology training programs for people with disabilities, the contributions of new access technology to the employment of people with disabilities, the ability of traditional rehabilitation centers to train people with disabilities, and the placement and employment of people with disabilities in new technologies.


Papers included in this report cover the following:

- The Task Before Us
- The Background and Setting

- New Technology Training Programmes for Disabled Persons in Great Britain
- The Effect of New Technology on the Employment of Blind and Visually Impaired Persons in Four Western European Countries
- Factors Associated with the Traditional Rehabilitation Centre's Ability to Train Disabled Persons for Advanced Technology Occupations
- Computer-Based Technology for Disabled Persons in Working Life: A Holistic Approach
- The Contribution of New Access Technology to the Employment of Disabled Persons in Japan
- New Technologies and the Employment of Disabled Persons in Israel
- New Technologies and the Employment of Disabled Persons in Four Developed Countries
- New Technologies in Rehabilitation: A Hungarian Perspective.

**Making a Difference-A Wise Approach.**

*National Easter Seal Society, 70 East Lake Street, Chicago, IL 60601-5907. 16-minute videotape. Available in one-half- or three-quarter-inch formats, \$50. Open caption versions also available.*

Recommended as a companion piece to *Part of the Team* and *Nobody is Burning the Wheelchairs*—two other videotapes from the National Easter Seal Society's *Americans with Disabilities Act (ADA) Resource Catalog*—*A Wise Approach* offers an opportunity to hear the philosophy of Virgil Craft, who lost both legs in a railroad accident more than 40 years ago. Since then, he has devoted his life to making a difference in the lives of those around him. His first achievement was the creation of the first blood bank in his hometown of Wise, Virginia. In addition, he has been involved in numerous volunteer efforts which have touched virtually every aspect of life in the community, including the schools, city government, the environment, and social service organizations. 



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(Continued from page 6)

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## Rehabilitation in Vermont

(Continued from page 34)

their families. Jobs may be scarce; but if one can work, one should.

In addition, there is an attitude that supports innovation. The smallness, the ruralness, easy communication, our unpoliticized environment, and even our poverty makes creativity easier. There is a willingness to make things work in spite of the problems.

People with disabilities face significant problems living here: lack of public transportation, architectural barriers, ice and snow, lack of industry, and isolation.

But Vermonters with disabilities retain the same qualities which make us all glad to be here—a perseverance and belief that things do work out in the end. 



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# AMERICAN Autumn 1993 REHABILITATION



**HIV/AIDS**



# Judith E. Heumann

## Begins Duties as Assistant Secretary Special Education and Rehabilitative Services



Judith Heumann, co-founder and vice president of the World Institute on Disability (WID) and an advocate for the rights of people with disabilities for nearly 25 years, was sworn in June 29 as Assistant Secretary, Office of Special Education and Rehabilitative Services (OSERS), the umbrella agency that oversees the Rehabilitation Services Administration, the Office of Special Education Programs, and the National Institute on Disability and Rehabilitation Research.

She was nominated by President Clinton on March 9 and confirmed by the Senate on June 23.

"Ms. Heumann has been a highly effective spokesperson and advocate for individuals with disabilities and will be a real asset to the Department," said U.S. Secretary of Education Richard W. Riley. Through her knowledge, leadership, and tenacity she has helped change both laws and perceptions about persons with disabilities, and as a result, has improved the lives of millions of Americans. I welcome her to our team."

When she was sworn in as assistant secretary, Ms. Heumann said:

"Twenty years ago, when I first became involved in disability advocacy,

whoever would have believed that people with disabilities would have made the gains we have made? We have seen the development of independent living centers. We have seen public schools begin to recognize that children with disabilities can go to school alongside nondisabled children and produce a valuable educational setting for all. But despite the gains that have been made, there is much work left to be done. Many policies and programs affecting the lives of millions of children and adults with disabilities and their families are now part of my responsibility.

"People ask me what am I going to do. Why did I take this job? I am taking this job because I believe in President Clinton's commitment to change for all Americans. Further, I believe in Secretary Riley's commitment to serve the needs of people with disabilities and his commitment to provide quality education for all students. Together we can make a difference. I am excited about working within the government with the many people who have great experience and a vision for a better future for all Americans.

"I intend to ensure that the issues affecting people with disabilities are seen as an integral part of the work of the Department of Education. I will work to provide for full and appropriate implementation of the Individuals with Disabilities Education Act (IDEA). I will work to ensure that children with disabilities will benefit from the Administration's Goals 2000: Educate America Act and from the recently announced school-to-work initiative jointly sponsored by the Departments of Education and Labor. I will also work to ensure full implementation of the recent amendments to the Rehabilita-

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# Self-Help Groups for HIV Seropositive People

*Terry Carlton, M.S.  
Richard Beck, Ph.D.  
Harry Allen, Ed.D.*

**R**ehabilitation and other counselors are increasingly encountering clients who are HIV seropositive (HIV+), with or without symptoms, or who have AIDS. Angell (1991) presents data which estimates the present HIV+ population in the United States at 1 million, and growing geometrically. Many of these will also have secondary disabilities related to addictions (Devita, Hellman, & Rosenberg, 1988). Researchers have noted a plethora of psychosocial reactions of HIV+ people and of people in their environment: anxiety, denial, shock, anger, sadness, bargaining, social isolation,

dangerous sexual bravado, social stigma, self-pity, fear of death, and religious persecution (Devita, et al., 1988; Hoffman, 1991; & Nichols, 1985). Suicide rates are prevalent in this population. Marzuk, Turney, Gross, Tarcliff, Morgan, Mann, and Hsu (1988) state that male AIDS patients between the ages of 20 and 59 are 36 times more likely to commit suicide than other men.

Holland and Tross (1985) have described a three-phase model of people who become infected with HIV, in which their responses are mediated by:

- medical factors (symptoms, course, and complications);
- psychological factors (personality, coping, and support); and
- sociocultural factors (stigma, custom, belief, and value).



Self-help groups can provide assistance in all three areas. According to Coates, Temoshok, and Mandel (1984), social support has a direct positive effect on the person's health. Smith (1989) points out that release from sympathetic nervous system reactions involved in anger, or those involved with the parasympathetic system, such as depression, have improved immunological function (Smith, 1989). Self-help groups can fulfill educational, moral support, spiritual, and/or religious needs and help prevent suicide through mutual support and encouragement (Beck, Carlton, Allen, Rosenkoetter, & Hardy, 1992). This article will present two self-help groups for HIV-infected people and will attempt to extract principles from the literature and from an analysis of data collected from a survey of these two groups. The authors are hopeful that this will facilitate the formation of more self-help groups.

## History

Corey (1990) notes that self-help groups are like therapy groups, in that both emphasize expressing feelings, encourage support, stress the value of affiliation, and attempt to change behavior. However, he notes differences in that self-help groups are more single-issue and emphasize inspiration, persuasion, and support, whereas therapy groups employ self-understanding, behavioral reinforcement, and member feedback. Corey cites Riordan and Beggs (1987) who described how counselors may use these groups as an adjunct to their own practices. Riordan and Beggs (1988) point out that there is a subtle difference between groups calling themselves "self-help" and those who label themselves "support" groups. This difference lies in the fact that the latter is often initiated by a professional helping organization or by an individual.

Corey (1990) states that the May 1986 special issue of *Journal for Specialists in Group Work* deals with the myriad of special issues addressed by these groups, which include victims of post-traumatic stress syndrome, spouses

whose partners are employed in stressful occupations, survivors of incest, bereaved persons, elderly victims of crime and violence, and relocated adolescents. Corey argues that the self-help groups stress a common identity due to their common life situation, and that this provides an acceptance and climate in which members may modify beliefs, attitudes, and feelings about themselves.

Kurtz (1982) makes similar claims for the success of the most important self-help group in recent decades in terms of influence—Alcoholics Anonymous (AA)—which was initiated in 1935 by two alcoholics, Bill Wilson and Dr. Robert Smith. In an existentially oriented work, he postulates that AA works because it revolves on the following principles:

- the members learn about their finitude as humans and that there are aspects of their lives that they cannot by themselves control ("essential limitation");
- the members find agreement and can put an end to their feelings of isolation in the idea of "mutual limitation"; and
- members acknowledge that they stand to gain greater personal independence through a "limited dependency" on the group and by a surrender to a higher power.

This paradigm has been repeated many times in other self-help and support groups such as Narcotics Anonymous, Overeaters Anonymous, and others.

Thus, though other self-help groups may not have the kind of philosophical development which is apparent in the AA movement, they all seem to share the principles of sanctuary, common identity and vulnerability, anonymity, a sharing of ways of dealing with negative feelings such as shame and guilt, and the management of a process for which people perceive a need for assistance. Two models of self-help/sup-

port groups are presented and analyzed below.

## The Urban Support Group

The model for this group is located at the Center for Attitudinal Healing, a private not-for-profit corporation in Marin County, California. The center is a spiritually-oriented, nondenominational support agency for issues such as life-threatening illness. At this center, various support groups for life threatened persons meet and are supported by its volunteers as well as professional staff employed here. In typical support group fashion, center staff initiated groups for HIV+ people and their significant others.

The center was begun in 1975 to provide a peer-support group for children with cancer. It achieved national fame and when it appeared on *The Phil Donahue Show* it won an Emmy for the show. The center's activities were soon spotlighted by *60 Minutes* and PBS's *Mr. Rogers' Neighborhood*, which won the Odyssey Institute Media Award for its presentation. Offering its services free of charge, the center espouses an approach to life that emphasizes that a person may choose peace rather than conflict, love rather than fear. Its philosophical bases are contained in 12 concepts which reflect the core of attitudinal healing (Allen, 1988):

1. The essence of our being is love.
2. Health is inner peace. Healing is letting go of fear.
3. Giving and receiving are the same.
4. We can let go of the past and the future.
5. Now is the only time there is, and each instant is for giving.
6. We can learn to love ourselves and others by forgiving rather than judging.

---

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7. We can become love finders rather than fault finders.

8. We can choose and direct ourselves to be peaceful inside regardless of what is happening outside.

9. We are students and teachers to one another.

10. We can focus on the whole of life rather than the fragments.

11. Since love is eternal, death need not be viewed as fearful.

12. We can always perceive others as either extending love, or giving a call for help.

Three support groups for HIV+ people are offered at the center, one in the afternoon, and two in the evenings of weekdays. A person can belong to more than one group at a time.

Members are invited into the group on referral by professional or volunteer staff after an intake interview. Information on the groups is available at medical clinics, churches, bars, and other local gathering places of the general public. At each meeting, a general orientation regarding confidentiality and structure is given before the meeting proceeds. The groups are conducted in accordance with the following guidelines and agreements (Allen, 1988):

1. We acknowledge that our aim is to work on ourselves, to give mutual support and to practice nonjudgemental listening and sharing.

2. We recognize that each person's process is important, and not our judgement of it. Being accepted where we are makes it easier to accept rather than judge others.

3. We share what works for us and others rather than giving advice. We let other people find their own answers.

4. By risking and exposing our own emotional states, we find common experiences which allow for joining.

5. We recognize each other as unique; we recognize that each knows himself/herself better than anyone else. If we listen to the voice within, we will find our best answer.

6. We are here to support each other's inner guidance and assist one another to focus on what is meaningful to each of us rather than to confront or preach.

7. The roles of student and teacher are interchangeable; they fluctuate from one to the other regardless of age or experience.

8. We work on being with others, seeing only the light and not the lampshade.

9. We accept and acknowledge that all information shared in group is confidential.

10. We agree to keep in mind that we always have a choice between peace and conflict; between love and fear.

Meetings include information of an educational nature; but the major focus of the meetings concerns the center's mission—to provide a spiritual framework for dealing with psychosocial problems related to HIV infection.

Confidentiality within the groups depends upon a week-by-week consensual and implicit agreement. It is very rare that people are worried about being revealed, partly perhaps because of the location of the center (San Francisco Bay Area has proportionately more AIDS cases than any other community in the country).

At each group meeting, members introduce themselves. The groups have open membership (no beginning or ending dates). The fact of attrition through death is perhaps the largest problem, not only in establishing a certain cohesion and group identity but also in terms of raising the anxiety of new members who see their fellows succumb.

Groups at the center are not incorporated as such, although the parent Center for Attitudinal Healing is incorporated, enabling the center to compete for private grant funding and to employ professional staff.

### **The Rural Self-Help Group**

The group chosen for this model is a self-help group for HIV-infected persons who live in and around Southern Illinois University at Carbondale. The U.S. Department of Health and Human Services and the U.S. Department of Education consider southern Illinois as rural when classifying the region for the purposes of research grants (Falvo, 1993). Though the authors also regard

this as a more rural model, it is atypical in its rurality with regard to the educational and professional level of its members due to the proximity of the university. Also, Carbondale itself is a medium-sized city, having a population of 40,000. There are, however, several characteristics of the city and the area which render it similar to rural areas in general: The city has no public transportation, unlike most other medium-sized cities; the members of the HIV group under study in this work are permanent residents of the southern Illinois geographical area and depend more upon their own transportation to access this group than do persons in the urban HIV study group; Southern Illinois University is generally considered by other residents of the southern Illinois geographic area to be a culturally distinct enclave; and Carbondale is 90 miles from a major metropolitan area (St. Louis). For these reasons, the authors have reasoned that the HIV group members in Carbondale may be subjected to rural cultural attitudes and values as well as to the typical problems of fewer services and resources than are their counterparts in San Francisco. The data from the study, then, should be interpreted cautiously in terms of an urban-rural distinction and should be considered as preliminary.

The Carbondale group is sponsored by a corporation, set up to organize materials and expenses which do not put undue burden on individual budgets and which, with legal status, can seek assistance from outside sources (a local attorney volunteered her time and the money for the filing fee to help the group incorporate in 1991). The corporation in this model is the Southern Illinois Region Effort for AIDS, Inc. (SIREA, Inc.). Both the urban and rural models, therefore, have found advantages in incorporation.

Although a support group for AIDS existed at Southern Illinois University at Carbondale's Counseling Center, it dissolved because the scheduled time for meetings was inconvenient; driving to and parking on campus was problematic; and many people were concerned about confidentiality, since the



university is the region's number one employer (increasing the possibility that a group member would run into a friend or acquaintance).

The new group was organized by the lead author, Terry Carlton, who has HIV infection; the chief aim of the group was assuring confidentiality in the referral and meeting process. A dual release of information was developed and distributed to area physicians identified as having patients who were either HIV+ or had AIDS. Referral/release of information forms were distributed in person after these physicians were sent a letter of introduction from the author's personal physician. Appointments were scheduled with each physician to present the forms and to review procedures for maintaining confidentiality. This activity led to the identification of a number of individuals interested in forming a grass roots level support group. A schedule for weekly meetings was then planned that would not conflict with members' work activities or recreational plans. By 1990, this group, calling itself "Staying Alive," had a core of regular members.

In the group's formative stages, meetings were rotated among members' homes; potluck dinners were used to promote friendship, care, and concern. In addition to providing a relaxed, comfortable atmosphere, the meetings were also used for the sharing of personal experiences and announcing treatment updates available from various sources. Members in turn would then share much of the information with their personal physicians; this gave the members a sense of empowerment and helped to forge a new interactive relationship between the group and area physicians.

By 1991, the group reworked its referral procedures. A brochure was created by members and distributed to area physicians, public health clinics, and psychologists. Interested persons were told to call "Linda" at the county health department; "Linda" would then suggest that the caller dial another telephone number and ask for "John," who was a member of the self-help group. No records of the transaction were retained. This procedure increased

<b>TABLE 1</b> <b>Characteristics of HIV+ Self-Help Group Members</b> <b>by Urban and Rural Environments</b>		
	URBAN	RURAL
AGE	41.6 yrs	40.0 yrs
SEX	8 Male 1 Female	12 Male 0 Female
SEXUAL ORIENTATION	7 Gay 1 Bisexual 1 Heterosexual	10 Gay 1 Bisexual 0 Heterosexual
MARITAL STATUS	0 Married 9 Single 0 Divorced	0 Married 9 Single 2 Divorced
RACE	0 Black 0 Hispanic 9 Caucasians 0 Asians 0 Other	1 Black 0 Hispanic 11 Caucasians 0 Asian 0 Other
EMPLOYED	8 yes 1 no	5 yes 7 no
EMPLOYMENT TYPE	1 Professional 1 Technical 3 Sales or Clerical	4 Professional 1 Technical 1 Sales or Clerical
SOURCE OF INCOME	7 Employment 1 Social Security	5 Employment 4 Social Security 1 Friends or Relative 1 School Loan
EDUCATION	3 Associate Degrees 3 Bachelors Degrees 3 Graduate Degrees	1 Associate Degrees 4 Bachelor Degrees 7 Graduate Degrees
Note: Figures that do not add up to the number of respondents are explained by missing data on the questionnaires.		

anonymity. To ease members' concerns about home security and confidentiality (since meetings were held at members' homes), members developed a written agreement on confidentiality and required persons referred to the group to meet informally with two representatives of the group at a "neutral" location. This informal meeting allowed prospective new members to obtain

more information on what to expect from participation in the group. It presented group representatives with the opportunity to emphasize the importance of confidentiality. Importantly, by meeting informally with two group members, the new member did not have to deal with the anxiety of coming in "cold" to a first group meeting; he or she knew that he or she would know at



least two people. This procedure had two additional inadvertent payoffs: no one was refused an invitation to join who came to the informal interview, and the screening interview became a motivator for attendance (perhaps due to the perception of being accepted).

Because these new procedures resulted in increased membership, a new meeting site was needed. A member was able to arrange a site near the university campus at the Catholic Newman Center. However, this location did not work out due to the nongroup traffic and concerns about confidentiality, nor were there facilities to continue the potluck dinner tradition. Ultimately, the group's relationship with area physicians resulted in a meeting location which was: unoccupied at meeting times; easily accessible and in a neutral location; "off the beaten path," which eliminated chance encounters with nongroup acquaintances; and had kitchen and dining facilities.

In addition to the weekly group meetings, there are also meetings for the corporation board and members at a location supplied by a member of the board of SIREA, Inc. With the assistance of the board (made up of local community professionals), three fund-raisers in the community have resulted in some financial resources for service program development. The business of the corporation is conducted by the board and volunteers; services are provided by volunteers recruited through the university (such as individual/group counseling provided by counselor training programs). The corporate treasurer was instrumental in having a certified public accountant complete the application for tax exempt status.

SIREA, Inc., now provides the following services to people with AIDS:

- sponsorship of the self-help group;
- a speaker's bureau on HIV infection;
- treatment information updates;
- an informal fact sheet for persons newly diagnosed;
- referrals to appropriate allied agencies;
- referrals to area healthcare providers;

- emergency financial assistance;
- coordination of services for individuals by case managers; and
- a "buddy" program.

The number of people receiving services from SIREA, Inc., and the self-help group now exceeds 30.

## Contrasting the Two Models

To provide a data-based comparison of the two models, a survey of members of both the rural and urban groups was undertaken.

## Method

A questionnaire was designed by the authors, approved by the university's Human Subjects Research Committee, and distributed at group meetings to members and persons contemplating membership.

The *total* confidentiality of the survey was assured by having the respondents send the completed forms to the address of one of the researchers at the university in an envelope with no return address; by having no identifying information on the questionnaire itself; and by providing a cover letter with the questionnaire which guaranteed confidentiality and reassured each potential respondent of their absolute right not to respond.

The information obtained from this study is purely descriptive and preliminary. However, the questionnaires were analyzed from the point of view of face validity, and responses to them do provide data in addition to historical facts which allow some tentative hypotheses.

## Results

The questionnaire sought demographic data from respondents as well as psychosocial perceptions. These data for both the urban and rural groups are shown in Table 1.

The data indicate that the urban and rural respondents are of similar average age (about 40), sex (predominantly male), sexual orientation (predominantly gay), and marital status (pre-

dominantly single), but that they differ with regard to the other categories. The rural group seems to have more unemployment, but those employed seem to have more professional occupations than the urban group. More of the rural group is on Social Security and its members have higher professional levels of education than the urban group, probably an artifact of the university's role in this community.

Turning to the psychosocial responses of both groups, this data is represented in Table 2 below.

The data in Table 2 seem to reveal the following. The rural self-help group members apparently drink more than their urban counterparts, although they appear to be light or moderate drinkers. Driving seems to be more of a factor for the rural group. Both groups seem divided in their concerns about confidentiality, both report similar symptomatology, insurance, and state support, and both rate medical treatment by doctors and hospitals as adequate (although the rural group is divided concerning the adequacy of professional services). The groups report similar psychological sequelae to HIV infection, except that the rural group appears less suicidal and guilty and has less difficulty coping.

The groups respond similarly to life expectancy and to reactions of families, friends, lovers, spouses, employers, counselors, doctors, and nurses (parenthetically, there was more missing data for these questions, perhaps revealing an ambivalence or other resistance to responding). However, the questions in this section generally appeared not to be optimal in view of the comments written in the margins of questionnaires. In view of question ambiguity, not much can be ascertained about the complex feelings regarding psychosocial reactions of members or others for both groups.

What does seem apparent from the data is that members of these groups have different personal goals regarding their membership. The rural members tend to rank more highly the social, recreational, and information/advice benefits of group membership, whereas

**TABLE 2**  
**Psychosocial responses of HIV+ self-help group members**  
**by urban and rural environments**

	URBAN	RURAL		URBAN	RURAL
<b>Report of drinking</b>			<b>Depressed</b>		
yes	2	8	yes	5	7
no	7	4	no	4	5
<b>Amount of drinking</b>			<b>Suicidal</b>		
Light	0	5	yes	5	1
Moderate	1	3	no	4	11
Heavy	1	0	<b>Angry</b>		
<b>Report of symptoms</b>			yes	3	4
Have symptoms	6	7	no	6	8
No symptoms	3	5	<b>Guilty</b>		
<b>Description of symptoms</b>			yes	3	0
Stable	5	3	no	6	12
Minor disruption	1	7	<b>Positive</b>		
Major debilitation	2	1	yes	7	8
Other	0	1	no	2	4
<b>Rating of insurance</b>			<b>Emotional roller coaster</b>		
<b>adequacy</b>			yes	4	7
Adequate	8	8	no	5	5
Not adequate	1	4	<b>Difficulty coping</b>		
<b>Receipt of state support</b>			yes	4	2
Receive support	4	6	no	5	10
No support	5	6	<b>Expectancy of how</b>		
<b>Rating of medical</b>			<b>HIV+ will affect life span</b>		
<b>treatment by doctors</b>			Very little	0	0
Adequate	8	10	May affect	6	6
Not adequate	1	1	Don't expect long life	3	6
<b>Rating of medical</b>			<b>Reactions of families</b>		
<b>treatment by hospitals</b>			Supportive	7	8
Adequate	8	10	Fearful		
Not adequate	1	0	Rejecting		
<b>Problems reported</b>			Don't know	2	4
<b>with accessibility</b>			Other		
<b>of professional services</b>			<b>Reactions of friends</b>		
<b>(other than doctors)</b>			Supportive	8	11
yes	1	6	Fearful		
no	8	6	Rejecting		
<b>Psychosocial sequelae</b>			Don't know		
<b>to HIV+ reported afraid</b>			Other	1	1
yes	4	6	<b>Reactions of lovers</b>		
no	5	6	Supportive	3	5
			Fearful		1
			Rejecting		
			Don't know		
			Other		1



**TABLE 2 Continued**  
**Psychosocial responses of HIV+ self-help group members**  
**by urban and rural environments**

	URBAN	RURAL		URBAN	RURAL
<b>Reactions of Spouse</b>			<b>Member of a support group?</b>		
Supportive	2	1	yes	9	10
Fearful			no	0	2
Rejecting			<b>For what purposes are you a member of a support group?</b>		
Don't know			Social recreational		
Other			yes	4	9
<b>Reactions of Employers</b>			no	5	3
Supportive	3	4	<b>Emotional support</b>		
Fearful		1	yes	9	5
Rejecting		5	no	0	7
Don't know	1		<b>Information/Advise</b>		
Other			yes	4	9
<b>Reactions of Counselors/Therapists</b>			no	5	3
Supportive	6	6	<b>Spiritual</b>		
Fearful			yes	8	0
Rejecting			no	1	12
Don't know			<b>What distance do you travel to support group meetings (average)?</b>	2.5 miles	22.4 miles
Other			<b>Do you drive?</b>		
<b>Reactions of Doctors</b>			yes	8	11
Supportive	7	11	no	1	1
Fearful			<b>Is there bus transportation available where you live?</b>		
Rejecting			yes	2	0
Don't know			no	0	2
Other	1		<b>Is transportation a problem in life activities?</b>		
<b>Reactions of Nurses</b>			yes	0	1
Supportive	8	11	no	2	2
Fearful			<b>Do you have concerns about confidentiality with your HIV?</b>		
Rejecting			yes	4	6
Don't know			no	5	6
Other					
<b>Reactions of General Public</b>					
Supportive	4	1			
Fearful	1	2			
Rejecting		2			
Don't know	1	3			
Other	5	1			

the urban members rank emotional support and spiritual benefits foremost. This distinction is consistent with the difference between the concepts of self-help groups versus support groups, with the latter receiving professional counseling or therapeutic support and leadership. It may also tend to reflect differing values between geographically and demographically different areas or between the two types of groups themselves.

## Discussion


The historical and questionnaire data yield to some interesting possibilities in view of the literature.

First of all, it seems apparent that the self-help group model seems well-adapted to rural environments, in that in these environments confidentiality is harder to protect than in urban environments. Therefore, to protect that confidentiality rural group members took special pains in terms of group procedures and meeting locations.

Second, it is apparent that groups develop their own style of becoming a dynamic unit interacting with environmental supports. They develop differing goals, orientations, procedures, etc., in conjunction with agency support, the background of members, the availability of support systems (e.g.,

medical) within the community, the philosophical basis that exists in a parent organization, and other factors.

Third, it seems apparent that both the support group and self-help group models are viable and they depend in their efficacy not only on the characteristics of group members, but also on the particular environmental factors in their communities. One type of group may be better under certain circumstances than another.

It is the hope of the authors that this presentation of two different models may elucidate the decision process for others interested in starting a group. 

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# AIDS: The Physical Therapist's Role in Rehabilitation

*Pamela A. Stanton, Ed.D., PT*

## Intervention

**T**he quality of life for people with human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) can be improved and expanded through physical therapy intervention. With more than 13 million people throughout the world infected with HIV, it is imperative that rehabilitation professionals be prepared to access and utilize all possible modes of effective treatment (PT Bulletin, 1992).

People with AIDS have needs that may involve the services of virtually every member of the rehabilitation team. The physical therapist is an important member of this multidisciplinary team, whose services include those that address the psychological, spiritual, vocational, and physical health of the individual. An understanding of the role of physical

therapist can facilitate the rehabilitation specialist's ability to make the best use of these professionals.

While AIDS is still regarded as a terminal illness, (Pamarola-Sune, Navia, Cordon-Cardo, Cho, & Price, 1986) survival rates have increased to the point where rehabilitation is a predictable and necessary part of the person's plan of care. Rehabilitation needs are usually the result of disabilities caused as a primary or secondary result of the HIV infection or disabilities or injuries that result from etiologies unrelated to HIV (O'Dell & Dillon, 1992; Galantino, 1992). In either case, physical therapy intervention may be divided into four major categories of goal-based activities. These are:

- *Management of Pain*
- *Maintenance of Strength and Endurance*
- *Independence in Self-Care*
- *Education*

## Management of Pain

Pain experienced by people with AIDS may come from any number of sources, ranging from those seen across the population in general to those more specifically associated with the sequelae of severe immune deficiencies (Wells, Frampton, & Bowsher, 1988). The key factor in pain as it relates to the role of the physical therapist is its effect on function. Pain may be the primary cause of a reduction in function (Goodman, 1990; O'Dell & Dillon, 1992). This can lead to a rapid loss of independence and increased reliance on caregivers. The physical therapist may use a combination of modalities and techniques for reducing pain. These include ultrasound, transcutaneous nerve stimulation (TENS), laser, and counter-irritation. Manual therapy may be particularly successful in virus related myelitis. Reports of success in using techniques called myofascial release and craniosacral therapy also have been published (O'Dell & Dillon, 1992; Galantino, 1992).



## Maintenance of Strength and Endurance

Since one of the hallmarks of AIDS is that it is a multisystem disease with a characteristically uneven clinical course, the maintenance of strength and endurance is critically important. In all cases, an individualized exercise program is designed after careful and thorough physical therapy assessment.

The intensity of exercises designed for the AIDS client range from light resistive exercises—similar to those used for chronically ill persons—to assistive exercises, which are effective when strength to complete the appropriate motion on an independent basis is lacking. Whenever possible, the individual should be encouraged to participate in physical activities to his level of tolerance (Levinson & O'Connell, 1991). Galantino and Pizzi (1991) report that they have found no data that support very aggressive exercise protocols. In fact, exercises that take the client to a point of fatigue may have negative consequences, including an increased feeling of a lack of control as well as general exhaustion. Based on the present body of literature, exercises should be limited to comfortable ranges that avoid fatigue (Spence, Galantino, Mossberg, & Zimmerman, 1990).

## Self-Care


Self-care includes those activities relating to dressing, washing, feeding, taking medications, wound dressing, and exercise that are routinely employed by the client (Galantino, 1992; Spence, Galantino, Mossberg, & Zimmerman, 1990; Levinson & O'Connell, 1991). Of particular importance to the physical therapist is the individual's ability to apply any necessary splints, braces, or other assistive devices necessary for maintaining function and independence. Techniques of energy conservation are also taught to enable the chronically ill person to achieve the maximum amount of self-care with the least amount of unnecessary effort.

## Education

Education for the caregiver as well as the person with AIDS is of critical importance. In addition to developing, evaluating, and modifying the plan of care for the patient, the physical therapist must be knowledgeable of and able to teach infection control to the client. Both the client and the caregiver must be carefully educated in methods to ensure that the activities of daily living are accomplished and that quality of life is maximized.

As the disease progresses, caregivers will become a more important part of the client's world. If they are to be effective, caregivers must be taught safe transfers from bed to chair as well as other important activities of daily living. Education to protect the health and safety of the caregiver is as important as that which pertains only to the individual with AIDS. (Levinson & O'Connell, 1991; Galantino & Pizzi, 1991; Galantino, 1992).

In all cases, AIDS education must include an in-depth coverage of *Universal Precautions* as defined by the Centers for Disease Control. Although sexual abstinence is the only real safe practice, those who remain sexually active should be educated in the safest procedures (Levinson & O'Connell, 1991).

In summary, the physical therapist's role in the treatment of AIDS related symptoms is an important one, and may include methods to reduce pain, increase strength and endurance, and maintain independence through self-care activities. Education that addresses all aspects of the client's life serves as the framework upon which safe, rational decisions can be made. AIDS is progressively becoming treatable. Effective and efficient treatment modalities can be selected only when the rehabilitation professional understands the scope of possibilities. Including the physical therapist in this process can greatly augment the productivity and quality of life for people with AIDS. 

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## **AIDS Policies and Education: What are Vocational and Residential Rehabilitation Providers Doing?**

**Results of a survey of rehabilitation providers conducted March–May 1991**

*This study reports on a comparison of the extent of rehabilitation provider involvement in implementing HIV policies and HIV prevention education programs in New York and Indiana. A survey was conducted of 219 members of the New York and Indiana State Associations of Rehabilitation Facilities (79 members in Indiana and 140 in New York). Approximately 70 percent of the agencies responding were either currently providing or planning to provide HIV education; about 50 percent of the agencies were currently providing HIV education; and 79 percent of the agencies had developed HIV policies. In New York, approximately 30 percent of the community rehabilitation providers indicated that they were rendering services to individuals with HIV/AIDS; this compares to 23 percent in Indiana. The results confirmed the trends for other HIV efforts: New York community rehabilitation providers had more policies and education programs in place at the time of the survey and expressed less interest regarding additional information on policies than the Indiana rehabilitation providers. The results also confirmed the need for a greater emphasis on: (1) policy development, particularly in the areas of testing and counseling; (2) HIV prevention education for program participants that is expressed in clear and straightforward language; and (3) rehabilitation services, including vocational, residential, mental health, counseling, and testing for people with HIV/AIDS.*

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**I**n recent years, the American public has been encouraged to provide HIV education/prevention programs, personally adopt safer sex practices (i.e., abstinence, condom use, and long-term monogamous relationships), and develop and implement policies regarding HIV infection, prevention, and accommodations in the workplace. At the same time, the public has received mixed messages concerning the value, necessity, or even the urgency of such programs and practices. In a report of the National Commission on Acquired Immune Deficiency Syndrome (1991a), *America Living with AIDS*, the commission suggests that messages, to be effective, must be much more direct than the early euphemisms such as "exchange of bodily fluids."



They recommend the use of “unvarnished language and communication that are both meaningful and acceptable to the particular community or group being addressed” (p. 21). According to the report, “More than a hundred people die in the United States every day of AIDS—one every 15 minutes—and the pace is accelerating” (p.11).

The purpose of this study was to collect initial information on the status of HIV-related educational activities and policies of vocational and residential rehabilitation providers in New York and Indiana, states which represent both the needs and circumstances in middle America and the tremendous problems occurring in large metropolitan areas. The intent was to gather information regarding:

- the extent of education for staff and program participants (clients);
- the extent of policy development and implementation;
- the extent of service provision to persons infected with HIV/AIDS;
- the strengths of the current HIV education programs operated by rehabilitation providers; and
- service provider needs and interest in obtaining further information about HIV education and policies.

The information from this initial baseline assessment has been used to develop an educational curriculum and recommendations for HIV education and policies. The curriculum is being piloted with community rehabilitation providers in New York and Indiana. The results should be available in January 1994.

Although the number of people with mental retardation/developmental disabilities (MR/DD) who have HIV/AIDS at this time is considerably lower than for the population as a whole, implementation of effective HIV education and HIV policies is still needed (Jacobs, Samowitz, Levy, J.M., & Levy, P.H., 1989; Crocker, Cohen, Decker, Rudigier, & Harvey, 1989; Kastner, DeLotto, Scagnelli, & Testa, 1989; Kastner, Hickman, & Belhumeur, 1989; Decker, 1989; McDaniel & Sells, 1989). As Jacobs, Samowitz,

Levy, J.M., Levy, P.H., and Cabrera (1991) have indicated, this population is at risk due to their vulnerability, sexual activity, presence in the community, and overall lack of sex education and information regarding safer sex practices.

Obtaining national data on the incidence of AIDS among people with mental retardation and developmental disabilities has been difficult due to policies regarding testing and confidentiality and the general overall low rate of testing for HIV. In a 1987 study of mental retardation/developmental disabilities centers in 44 states, 45 people were reported to be HIV positive (HIV+) (Kastner, Nathanson, Marchetti, & Pincus, 1989). A 1990 report by Crocker and Cohen (1991) includes a reference to estimates of the number of adults with mental retardation infected with HIV virus; the revised estimate is now at “over 300.” Because of the long incubation period (up to 10 years), the actual number of people with developmental disabilities/mental retardation and AIDS is certain to be higher than the estimated 300.

At the individual state level, more data regarding the number of people with MR/DD who are at risk are available. In a survey of 67 adolescents and adults with MR/DD in Oregon, 39 percent of the adults and adolescents were identified as engaging in behaviors which are high risk for transmission of HIV/AIDS (Hylton, 1989). And in connection with educational needs, only 27 percent of those program participants provided accurate answers to the question: “What can you do to keep from getting AIDS?”

Residential, vocational, and medical rehabilitation providers are encountering HIV/AIDS as they receive referrals to serve persons with AIDS in preschools and daycare and in residential, vocational, medical, and mental health settings. Community rehabilitation providers also are encountering HIV/AIDS as in other workplace settings, through staff and clients who become infected. Because rehabilitation providers are handling more and more HIV/AIDS-related issues, the need to develop HIV

education programs and policies is growing.

This study examines the extent of rehabilitation provider activities regarding HIV prevention education and the development and adoption of policies regarding AIDS for two states with different histories and circumstances surrounding the incidence of HIV/AIDS. In September 1991, Indiana reported a total of 1,240 AIDS cases since the Centers for Disease Control began collecting data in June 1981. This figure is approximately the overall median number of cases of AIDS for an individual state. In comparison, the cumulative total of cases of AIDS in New York State was 40,127. The cumulative total for New York City alone was 34,896; this compared to 586 for Indianapolis. Only Los Angeles and San Francisco came close to New York City in cumulative numbers of cases (with Los Angeles reporting 12,714 and San Francisco reporting 10,845) (Centers for Disease Control, 1991).

## Participants

Members of the New York State and Indiana State Associations of Rehabilitation Facilities (NYSARF's and INARF's) were mailed questionnaires regarding HIV education and policies. Questionnaires were mailed to 219 rehabilitation providers, 140 in New York and 79 in Indiana. Most of these deliver both residential and vocational rehabilitation services and offer a variety of services, including comprehensive vocational evaluations; supported, sheltered, and competitive employment; and independent, semi-independent, and group living arrangements. The Indiana and New York members, while offering similar services, vary in terms of the populations served and size of operations. New York includes proportionately more agencies that provide

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services to people with disabilities other than mental retardation, such as deafness and blindness/visual impairment. Indiana on the other hand, primarily serves people who have developmental disabilities, mild learning disabilities, and mental retardation. The size of the agencies also varies; more New York members are large, with larger operating budgets. For example, according to records of the National Association of Rehabilitation Facilities, \$3.9 million is the largest amount reported for annual salary expenditures by Indiana members; in New York, six agencies report annual salary expenditures ranging from \$4 to \$26 million.

## Instrument

A two-page survey was developed to measure service provider involvement regarding the following:

- HIV/AIDS Education;
- HIV/AIDS Policy Development; and
- Services to People with AIDS/HIV.

A list of topics addressed under each area is presented in Table 1.

Most questions could be answered with a "yes" or "no" or by checking applicable items. Respondents were also encouraged to provide additional comments and copies of curricula and policy statements already in use.

## Procedure

A written questionnaire was mailed to each member of the Indiana and New York State ARF's in March 1991; a copy of the questionnaire is included in the appendix. The two state associations provided a cover letter or notice in their routine association correspondence encouraging responses. A second questionnaire was sent to nonresponding members in May 1991.

Overall, 118, or 50.3 percent of the ARF members responded: 31, or 39 percent, from Indiana and 86, or 61 percent, from New York. Although every agency did not respond to every question, most respondents answered all of the questions, with approximately one-half of the agencies providing responses to the

**Table 1**  
**Content covered by Needs Assessment/Questionnaire**

### (1) HIV/AIDS Education

- Current or planned education or training of program participants
- Major content areas
- Use of formal curriculum
- Best features of curricula being used
- Issues or problems encountered
- Reasons for *not* providing consumer AIDS/HIV education, if applicable
- Interest in obtaining additional information

### (2) HIV/AIDS Policy Development

- Status of policy development
- Policy areas covered (if applicable)
- Interest in obtaining additional information

### (3) Services To People With AIDS/People Who Are HIV+

- Current provision of services
- Services being provided
- Interest in providing services if not already doing so

open-ended questions on education and/or services or supplying information under "additional comments."

## Results: Objective 1. To Determine the Extent of Service Provider Involvement in Providing HIV/AIDS Education.

When asked if their agency was currently providing, or planning to provide, HIV/AIDS education to program participants, 70 percent of the INARF and 72 percent of the NYSARF members responded affirmatively. Fifty-five percent of the New York members and 47 percent of the Indiana members indicated they were currently providing HIV/AIDS education to program participants.

About 70 percent of those either currently providing education and training or planning to during 1991 indicated that the information is being supplied to both staff and program participants. Eleven percent of the agencies (primarily NYSARF members) reported providing or planning to provide HIV education to people in addition to staff and program participants, such as family members and other agencies.

## Content

Agencies were asked to identify whether the HIV education materials included information on the nature of the HIV infection, risky behavior, risk reduction, or other content areas. As indicated in the following table, risk reduction was included by the largest portion of agencies and by all of the Indiana respondents.

Responses were generally similar across the two states, with three out of four respondents indicating that all three content areas were included in their program. Forty-four percent of the New York agencies indicated that other areas were also included; none of the Indiana agencies identified additional content areas. The most frequent additions were confidentiality and other policy areas (e.g., nondiscrimination, informed consent) and appear to refer to education for staff rather than program participants. INARF members also were less apt to cover the nature of infection, although this was included in 75 percent of the programs.

A majority (53 percent) of those currently providing or planning to offer HIV/AIDS education to program participants indicated the use of a formal

curriculum, with approximately 60 percent of the New York respondents reporting its use compared to only 37 percent of the Indiana agencies.

Best Features

A total of 63 agencies—10 from Indiana and 53 from New York—provided comments on what they found to be the best features of the curriculum or education program they are using. The responses were generally similar, with New York agencies covering a broader scope of features because of the larger number of respondents. Comments were generally favorable on educational programs, which participants said were written in clear and direct language, were designed for the knowledge level of program participants (many of whom have cognitive impairments), and included current information. Curricula which provided recommendations for flexible use and adaptation for different circumstances, opportunities for group discussions and individual sessions, and the use of local consultants from agencies such as the Red Cross and Planned Parenthood also were viewed positively by the respondents.

The responses are presented in descending order of frequency in Table 4.

Issues/Problems Encountered

A total of 55 agencies, 12 from Indiana and 43 from New York, provided information on concerns and problems. The New York agencies' comments tended to reflect their experience in implementing an HIV prevention curriculum in their individual agencies, while the problems for program participants of the Indiana organizations centered around staff discomfort in relating to HIV/AIDS and HIV/AIDS education and prevention.

The primary areas of concern in both states were about the effectiveness of the education itself, including:

- how well it was targeted to people with mental retardation, especially those whose retardation is considered

Table 2 Status of HIV/Aids Education			
	Percentage of Respondents		
	INARF	NYSARF	Combined
Providing now	47%	55%	53%
Planning in 1991	23%	17%	19%
No	30%	28%	28%

Table 3 Content Areas			
	Percentage		
	INARF	NYSARF	Combined
Nature of infection	75%	87%	84%
Risky Behaviors	90%	90%	90%
Risk reduction	100%	92%	94%
All three areas	75%	74%	74%
Other content areas	0%	44%	33%

Table 4 Comments Regarding Best Features of HIV Education Programs	
—	<i>Targeting:</i> based on the knowledge level or needs of individuals, adaptable/flexible curriculum, "appropriate level"
—	<i>Content:</i> universal precautions, completeness/comprehensiveness, description of high-risk behavior, "current information"
—	<i>Style:</i> direct, factual, simple, clear, practical/relevant, non-threatening
—	<i>Presenters:</i> expert consultants, HIV+ individuals, use of local resources
—	<i>How presented:</i> 1:1, small groups, discussion, engagement of audience participation, individualized attention
—	<i>Media:</i> video, handouts, descriptive brochures, visual aids, resource materials (all New York)
—	<i>Structure:</i> use of post-tests, use of repetition, "builds progressively"

in the moderate range or below, and targeting for persons with other disabilities (e.g., serious mental illness);

- concerns about retention of information; and
- the transfer of the education to "real life" situations.

A few agencies in each state mentioned some dissatisfaction with the content or media of their current program (e.g., keeping up-to-date). Somewhat surprisingly, only six agencies (four in Indiana, two in New York) identified parental resistance as an issue.



## Why Organizations Are Not Providing or Planning to Provide HIV Education

Twenty-five agencies provided information on their reasons for not providing HIV/AIDS education to program participants. The primary reasons in both states was lack of interest or that it was a low priority, followed by resistance from various sources, including sponsoring organizations, staff, and parents, and being in a "conservative community." Nearly 90 percent of respondents in both states—a total of 91 agencies overall—expressed interest in obtaining additional information regarding HIV policies and education programs designed for rehabilitation providers.

### Results: Objective 2.

#### To Determine Rehabilitation Provider Activities and Needs Regarding HIV/AIDS Policy Development.

Responses on the status of HIV/AIDS policy development indicate that a considerable majority (79 percent) of the organizations currently have policies in one or more of the areas specified (staff employment, nondiscrimination, education/training, testing and counseling, and confidentiality). New York ARF members, however, were much more likely to have developed policies (83 percent vs. 68 percent among Indiana members), to have policies in place in each of the individual five areas listed, and to have them across all five areas (54 percent vs. 33 percent). Many rehabilitation agencies reported policies in place regarding the use of universal precautions, providing staff training during orientation and annually, and policies regarding record keeping and disclosure of HIV status. Fifteen organizations (10 in New York and 5 in Indiana) had policies in additional areas.

The following table indicates the policy areas covered by the 88 organizations responding to this question.

**Table 5**  
**Policy Areas**

	Percentage		
	INARF	NYSARF	Combined
Staff employment	62%	90%	83%
Non-discrimination	76%	94%	88%
Education/training	71%	88%	66%
Testing and counseling	43%	58%	55%
Confidentiality	62%	54%	49%
All five areas	33%	54%	49%

### Interest In Additional Information

Nearly 80 percent of the respondents indicated that they would like additional information on HIV/AIDS policy development. A significantly higher portion of INARF organizations (87 percent) than NYSARF members (76 percent) expressed this interest.

### Results: Objective 3.

#### To Determine the Types of Services Rehabilitation Providers are Giving to People with AIDS or Who are HIV+.

Of 108 agencies answering a question on current service provision to people with AIDS/HIV, 30 percent indicated that they were currently providing services and another 9 percent reported that they did not know whether they were or not. Current service provision to this population was more frequent in New York than in Indiana (32 percent vs. 23 percent).

### Services Being Provided

A total of 29 organizations, 7 INARF members (23 percent of the Indiana respondents) and 22 NYSARF members (28 percent of the New York respondents), furnished information on the services they were providing to people who are HIV+ or have AIDS, as follows:

- employment/rehabilitation: 62 percent;
- clinical and support services: 38 percent (New York only);

- services to children with HIV: 14 percent;
- residential services: 7 percent; and
- education and prevention: 7 percent (New York only).

Organizations answering the question reported providing sheltered employment, competitive and supported employment, rehabilitation services, vocational training, residential services, infant development, and "whatever is needed" to persons with HIV/AIDS.

An additional six agencies (21 percent of the 29 total respondents to this question) reported providing the full range of agency services or "whatever is needed." Thirteen agencies (1 in Indiana and 12 in New York) reported that they did not know if they were providing services to people with HIV/AIDS.

### Interest in Providing Services

Organizations *not* providing services to this population were asked if they would be interested in doing so. Sixty-four responded to the question (54 percent of the total respondents). Of these, a total of 47 indicated either "yes" (41 percent) or that they would provide services "as needed" (6 percent). Thirty-three said that they were not interested. Among those not providing services, 62 percent of the Indiana members compared to only 47 percent among New York members indicated they had no interest in providing services. Overall, however, the combined total of those already providing services and those interested in



or willing to provide services—while proportionately greater in New York than in Indiana—was nearly 60 percent of the organizations responding to the questions on services.

Thirty-five agencies, primarily in New York State, provided additional comments about services to people with AIDS or who are HIV+. The most frequent comment by organizations in both states was a willingness to serve the HIV population; a strong majority of these respondents, however, indicated that they would provide their regular services rather than establish any specialized services targeted to this population. The second most frequent response (New York only) was that they did not have access to information on program participants who might be HIV+, or that confidentiality policies at their agency precluded them from providing such information.

## Implications

A strong majority of Indiana and New York members are concerned about HIV/AIDS, are taking steps to educate program participants and staff, have developed policies on HIV/AIDS, and are interested in obtaining further information on both education and policy development.

The primary difference between the two states is that the New York membership is more involved with HIV policy and education issues. This is evidenced by the higher proportion of organizations that are *currently* providing education to program participants, proportionately more comments on actual experience with curricula, and the higher percentage with policies already in place. However, this is in keeping with the magnitude of the AIDS problem in New York. For example, in New York State, the leading cause of death among Hispanic children 1 to 4 years of age is AIDS; AIDS is the second most frequent cause of death among black children of the same age (GAO, 1991).

Furthermore, in New York City, officials are projecting that approximately 20,000 children will be orphaned due

to AIDS in the next few years (National Commission on Acquired Immune Deficiency Syndrome, 1991b). Intravenous drug abuse and prostitution in New York contribute substantially to the number of AIDS cases as well. The impact of AIDS in New York is far-reaching and additional efforts are needed to both prevent the spread of AIDS and assist those who are already infected.

## Testing and Counseling

In the current study, 79 percent of all the organizations reported having AIDS policies in place. However, agencies were much more likely to have policies regarding AIDS prevention, staff training, and confidentiality in place than they were to have policies regarding HIV testing and counseling. Only 55 percent of all organizations, 58 percent in New York and 43 percent in Indiana, reported having such policies. The sheer numbers of cases of HIV (particularly in New York), along with the general recognition of the sexual activities and vulnerability of persons with developmental disabilities and mental retardation (Jacobs et al., 1991) support the need for comprehensive policies, including policies regarding testing and counseling.

The relative lack of development of policy regarding testing and counseling, despite its prominence as a policy issue nationally, suggests that this may be an area requiring special attention. The importance of testing and the need for increased testing has also been highlighted in a recent report of the United States General Accounting Office (June 1991). Testing of persons with disabilities and the staff who work with them will increase as the number of people in this population group with AIDS increases and as the general awareness of the American public increases; organizations will need to be ready with policies that address testing, counseling, and confidentiality and, like education, are designed especially for their service populations.

The desirability of developing policies regarding HIV/AIDS for rehabili-

tation programs is substantiated not only by the AIDS statistics, but by recommendations of professionals working in the AIDS arena. Kastner et al. (1991), for example, have indicated that service providers should be aware that they may be held liable if they:

- fail to treat individuals with HIV/AIDS;
- discriminate in regard to the quality or type of services provided or the individuals who are deemed eligible to receive such services;
- breach confidentiality; or
- fail to provide a safe environment and prevent negligent transmission.

The American Bar Association (Rennert, 1991) has emphasized the need for programs providing services to individuals with HIV/AIDS to be sensitive not only to the broader policy areas, but also to the individual circumstances, and the need to maintain confidentiality not only concerning AIDS status, but also concerning related HIV information such as testing and counseling or the presence of opportunistic infections associated with AIDS.

## HIV Education

From the survey of rehabilitation providers in New York and Indiana, two primary HIV education interests emerged:

- *Reaching individuals with mental retardation effectively*—targeted curricula, materials that are simple and direct, use of videotapes, brochures and other media not requiring high levels of reading ability, ways to help people with cognitive limitations transfer the knowledge from the education program to “real life” experiences, and ways to promote or verify retention of information; and
- *The importance of approaches that can be tailored to individuals*—targeting to people based on their current HIV risk (e.g., frequent sexual activity with multiple partners); one-to-one education; curricula that can be adapted to different levels of knowledge, learning styles, or level of disability; and approaches that are sensitive to the discomfort and fears



that many program participants experience in learning about HIV/AIDS.

There was surprisingly little concern regarding family or community resistance to HIV/AIDS education of program participants, especially considering the attention to this issue nationally (e.g., the Centers for Disease Control requirement that education programs funded by CDC be approved by a community review committee). There was also no mention of coordination with other agencies providing services to program participants receiving education, or to any problems with such agencies.

The American Bar Association (Renkert, Parry, & Horowitz, 1989) cautions that service providers who are aware of sexually active residents but fail to provide appropriate information about HIV transmission may be liable for perpetuating "an environment that is constitutionally unsafe" (p.69). In a discussion of the duty of service providers to protect clients and employees from HIV transmission, the American Bar Association explains that it is far preferable to educate individuals regarding HIV transmission and how to reduce the risks of transmission than to either prevent individuals from engaging in sexual activities (which may violate individual rights) or warn an individual that a partner may be HIV+ (thus risking a breach of confidentiality). More materials on HIV prevention that are presented at a level appropriate to the learning abilities of individuals with cognitive impairments such as mental retardation are needed. These materials need to be presented in a way that provides for mastery of essential concepts; for many people, this will necessitate repeated practice and feedback to facilitate skill generalization.

## Services

Although New York members were more likely than Indiana members to be providing services to people with AIDS or who are HIV+, over 60 percent of the combined respondents were not providing rehabilitation services to people with HIV/AIDS.

The most significant finding, however, is that 67 organizations—more than two-thirds of the respondents—were either currently providing services to this population or interested in doing so, reflecting a clear commitment to service and to nondiscrimination.

It is also clear from the survey that, at the time it was conducted, there was relatively little interest in the development of new specialized services targeted to the HIV population or in providing services to people with AIDS or who are HIV+ who do not meet existing eligibility criteria. On the other hand, the willingness of the majority of the rehabilitation providers to serve this population indicates a need for further information on strategies to provide existing services effectively.


Rehabilitation providers in New York and Indiana, as across the rest of the nation, must grapple with dispensing appropriate services while keeping the risk of transmission low through universal precautions and the adoption of appropriate policies.

## Summary

The primary implication of the current study is that rehabilitation providers need and want additional information on targeted educational programs that are effective. Furthermore, rehabilitation providers need more information on policies, particularly in the area of counseling and testing.

Another implication is that the majority of organizations provide or are interested in providing their *regular* services to the HIV population. Information and technical assistance to these programs will continue to be needed as services increase and additional questions regarding policy and education also arise.

Regarding differences between the two states, the slower rates of implementing educational programs and of policy development suggest that technical assistance and information provided to Indiana members may need to be more comprehensive than that provided to New York members. New York also may have more members who are interested in "fine tuning" their

programs and policies. At the same time, both states have several members who are not providing education or who have gaps in their HIV policy structure and who want further information and assistance. 

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**APPENDIX**  
**NEEDS ASSESSMENT/BASELINE DATA**  
**INDIANA - NEW YORK**

**QUESTIONNAIRE**

**AIDS/HIV Education**

1. Is your facility currently providing HIV / AIDS education or training to consumers? Yes \_\_\_\_\_ Planning to in 1991 \_\_\_\_\_ No \_\_\_\_\_

If "yes" or "planning to in 1991," please complete below If "no," please skip to question number 5.

Education directed to: Consumers \_\_\_\_\_ Staff \_\_\_\_\_ Other (specify) \_\_\_\_\_

Education is directed toward the following areas: Nature of HIV / AIDS infection \_\_\_\_\_

How HIV infection spreads / risky behaviors \_\_\_\_\_

Ways in which to reduce risk of HIV infection \_\_\_\_\_

Other (specify) \_\_\_\_\_

2. Are you using / planning to use a formal curriculum? Yes \_\_\_\_\_ No \_\_\_\_\_

If "yes," please send a copy or other descriptive information to:

Christine Y. Mason, Ph.D., The National Association of Rehabilitative Facilities, P.O. Box 17675, Washington, DC 20041

3. Please list briefly what you feel are the *best features* of your Consumer HIV / AIDS education program: \_\_\_\_\_

4. Please describe briefly any *issues/problems encountered* regarding your HIV / AIDS education program: \_\_\_\_\_

5. If your organization is *not* doing HIV education, why not? \_\_\_\_\_

6. Are you interested in obtaining more information on HIV / AIDS prevention and education? Yes \_\_\_\_\_ No \_\_\_\_\_

**HIV/AIDS Policy Development**

1. Does your agency currently have policies in relation to HIV / AIDS? Yes \_\_\_\_\_ No \_\_\_\_\_

If "yes," please indicate in which areas: \_\_\_\_\_

\_\_\_\_\_ Staff employment (e.g., non-discrimination)

\_\_\_\_\_ Non-discrimination re: consumers

\_\_\_\_\_ Education / training in prevention and risk reduction

\_\_\_\_\_ Testing and counseling

\_\_\_\_\_ Confidentiality

\_\_\_\_\_ Other (specify)

2. Are you interested in more information on HIV / AIDS policy development? Yes \_\_\_\_\_ No \_\_\_\_\_

**Services to People with AIDS/People who are HIV positive**

1. Are you currently providing services to people with AIDS or who are known to be HIV positive? Yes \_\_\_\_\_ No \_\_\_\_\_

If "yes," what services are being provided? \_\_\_\_\_

If "no," do you have any interest in offering or developing services to this population? Yes \_\_\_\_\_ No \_\_\_\_\_

**Other Comments** \_\_\_\_\_

**Person completing questionnaire:**

Name / Title \_\_\_\_\_

Facility \_\_\_\_\_

Address \_\_\_\_\_

Telephone \_\_\_\_\_

Please attach an extra page if more space is required to reply.



# Understanding and Counseling Special Populations with HIV Seropositive Disease



*Richard Beck, Ph.D., CRC*  
*Terry Carlton, M.S.*  
*Harry Allen, Ed.D.*  
*Linda Rosenkoetter, M.S.*  
*Kim Hardy, M.S.*

People infected with the human immunodeficiency virus (HIV) will likely constitute a growing number of rehabilitation clients in the years ahead. HIV positive (HIV+) patients are considered disabled under the law (Americans with Disabilities Act)

and the new legislation will guarantee to them certain civil rights in employment, facility and service accessibility, and others for which the counselor may advocate. The absolute number of HIV+ people is growing geometrically, with 1 million people now affected (Angell, 1991) and their lifespan with new drugs having risen to 10–15 years post-diagnosis. This disease will present new challenges to rehabilitation counselors, although rehabilitation professionals have had other clients with life threatening illnesses (e.g., cancer, heart disease).

Those new challenges will come from two directions:

- HIV+ patients will often have secondary disabilities. For example, IV drug users constitute 29 percent of AIDS patients (Devita, Hellman, & Rosenberg, 1988).

- Counselors will be increasingly faced with problems of countertransference (Macks, 1988; Sorenson, Costantini, & London, 1989).

Besides these new challenges, special subpopulations within this group will require either special attention to or



emphasis on specific variables or may require completely unique approaches in assessment and counseling (e.g., clients with cultural backgrounds different from those of the rehabilitation counselor). These subpopulations include rural clientele, women, minority clientele, addicts, and homosexuals.

The stigma which will attach to these clients may be much greater than that experienced by other, more traditional rehabilitation, clientele, and many clients may be doubly stigmatized since AIDS usually affects people already stigmatized (Angell, 1991). The demands on confidentiality and psychosocial counseling skills of the counselor will be commensurately greater with this group (Faltz & Madover, 1987; Sorenson, 1989). In addition to these skills the counselor will need to pay close attention to skill areas which he or she may not have developed in the past, such as medical case management and sexuality counseling (Carballo & Miller, 1989).

The authors subscribe to the view of rehabilitation counseling offered by Thomas, Thoreson, Butler, and Parker (1992): "... the importance of a professional counseling relationship to rehabilitation is in the amelioration of handicaps created from the cumulative impact of psychosocial and physical barriers by people with disabilities" (p. 207). This paper, then, will elaborate these handicaps caused by HIV infection for special populations in particular, with a relevant literature review and suggestions for counseling programs which we have found promising for dealing with these handicaps.

## Models of Psychosocial Reactions to HIV+

Holland and Tross (1985) noted that a person's response to HIV infection is mediated by medical (symptoms, course, and complications), psychological (personality, coping, and support), and sociocultural (stigma, custom, belief, and value) factors. A phase theory of reaction to HIV infection has been developed by Nichols (1985), where reactions can be ascribed to three stages:

- *crisis*

- *transitional*
- *deficiency*

The reactions to each phase can be described along a continuum from maladaptive to adaptive.

The *crisis* phase involves periods of anxiety and denial, with shock, guilt, anger, sadness, bargaining, and acceptance. The negative reactions (denial, anger, bargaining, and guilt) may cause additional problems for the person, such as further physical damage, social isolation, and other maladaptive behavior, such as drug abuse and dangerous sexual bravado (Devita, Hellman, & Rosenberg, 1988).

The *transitional* phase begins when denial is no longer the dominant emotion, but is superseded by periods of anger, guilt, self-pity, and anxiety. According to Nichols (1985), patients attempt to find meaning in their disease ("Why me?"), which is aggravated by social rejections, loss of self-esteem, changes in identity, and personal values. At this stage, the person is in great need of psychological counseling because of the great threat of social withdrawal.

Finally, in the *deficiency* stage, the person achieves and becomes comfortable with a new identity and accepts the limits imposed by his/her disease on his/her life. Oftentimes, people who are HIV+ "feel less victimized by life, become less ego-centric, and find satisfaction in altruistic and community activities" (Nichols, 1985, p. 766).

Another model of psychosocial adaptation to HIV+ disease is that of Hoffman (1991), which postulates four primary components:

- the *special characteristics* of the infection;
- the role of *social support* in the infected person's life;
- the *characteristics of the situations* or transitions the infected person faces; and
- the *characteristics of the client*.

## Special Characteristics

Three characteristics apply to this component:

- HIV infection is a chronic progressive disease with a terminal prog-

nosis, and proceeds from a state of being symptom-free to decline (characterized by full-blown AIDS);

- social stigma is associated with the disease itself and also with those previously stigmatized, such as gay men or needle-using addicts; and

- HIV infection strikes a certain age group, usually young adults aged 25 to 45 whose productive years are being severely disrupted.

## Social Support

This model views social support from both personal and institutional perspectives.

First, the patient experiences a fear of interpersonal isolation and loss of relationships; and these fears are often realized. The patient often may feel "toxic" and withdraw from intimacy with others, including friends, families, and lovers. Hoffman reports that it is in this area in which support groups are particularly helpful and that patients who are involved with them are less dysphoric.

Second, the data on gay men suggest that they often have very limited number of people in their support systems and that this number may diminish with a diagnosis of HIV infection. When combined with other loss problems, this diminution becomes acute.

Third, institutional support is reduced, and takes the forms of unemployment (as the disease progresses), religious disaffiliation (since some religions see HIV infection as associated with sin), and a scarcity of community

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services available to seropositive people. Oftentimes, even AIDS support groups tend to target only white gay males as their primary members.

### Characteristics of the Situation

This category has several subelements:

- the source of the infection;
- timing and latency period from infection to symptoms;
- role changes; and
- the variability in response to each of these factors.

Each person will respond differently to the manner in which the disease was contacted. Feelings ranging from guilt to blame are often associated with such attribution. Secondly, because of the long latency period that exists between the time of infection and the outbreak of symptoms, people may be living lifestyles at the time when symptoms appear that are totally different than those associated with the period of infection. There is also the sense of being cheated out of life, of being old before one's time. People who become seropositive face multiple role and role identity changes. They may be rejected by friends, families, or lovers. They may move from employed to unemployed, from healthy to sick, from independent to dependent, and so on. Finally, people move through various stages in response and adjustment to their disease. Such stages have been described as: "initial crisis, early adjustment, acceptance, and preparation for their death" (p. 483). Each stage is dealt with by the person in his/her own idiosyncratic style. Each of the variables associated with the characteristics of the situation or transition plays a major role in the individual's response to life and each is responded to in terms of the personality and social circumstances of the individual.

### Characteristics of the Client

This category focuses on six variables:

- the psychosocial competence of the person;
- the person's cognitive appraisal of his/her disease;

- the person's gender and gender role identity;
- the person's race, ethnicity and social class;
- the state of the person's health; and
- the person's lifestyle associated with HIV infection.

Psychosocial competence is associated with self-esteem, coping skill, emotional hardiness, and beliefs of self-efficacy. Interactions among these variables may explain the person's success or failure in handling life events. Also, the way a person evaluates and appraises an event or circumstance governs the way he or she will emotionally and behaviorally respond to it. Characteristics of special populations engender a still broader diversity of response that complicates medical and psychosocial management of the disease.

Hoffman also mentions that medical perspective of HIV infection has changed, from one in which people were said to have either ARC or AIDS to one in which HIV+ people are diagnosed as asymptomatic or symptomatic or as having AIDS. Changes in health yield changes in life performance; the fact that specific behaviors (alcohol abuse, illicit drug use, venereal disease, etc.) suppress the immune system places behaviors and health status in a reciprocal dance which treatment personnel must acknowledge.

### Countertransference

There is an entire body of research which treats the problem of negative counselor attitudes towards clients with disabilities, but the HIV+ patient presents a completely new twist on the problem.

First of all, the counselor may worry about problems of contagion. Gerbert, Maguire, Badner, Altman, and Stone studied the reactions of health professionals to AIDS (cited in Sorenson, 1989), and found the main reaction was that of fear.

Second, the counselor may have to deal with negative attitudes towards secondary disabilities (e.g., drug addiction) and feelings of homophobia.

*Skill in grief counseling will need to take into account the pain, anger, fear, guilt, helplessness, and hopelessness of patients' families.*

For instance, Faltz and Madover (1987) noted that counselors often take the attitude that substance abuse will somehow make the AIDS patient's life easier to endure. Or, according to these authors, they may take moralistic approaches, such as believing that the patient must hit bottom before intervention may be successful or that "they got what they deserved."

And, third (and perhaps most important), the counselor must deal with his or her own feelings about death, which are usually handled through denial (Yalom, 1980). Moreover, the counselor may be confronted with difficult client adjustment problems whose central referent is death anxiety, and the counselor may have difficulty in handling these problems. Yalom (1980) cites various empirical studies which allude to the central role of death anxiety in severe obsessional illness, hyperventilation syndrome, hypochondriasis, and depersonalization syndrome. However, the major concomitant of death anxiety in the succumbing direction seems to be depression, which has implications not only for management of the disease, but for rehabilitation programming as well.

Skill in grief counseling will need to take into account the pain, anger, fear, guilt, helplessness, and hopelessness of patients' families (Carballo & Miller, 1989). Additionally, counselors will have to become involved in areas of counseling which they may have avoided previously, such as that of sexuality.



## Americans with Disabilities Act

The 1990 Americans with Disabilities Act (ADA) provides protection for HIV+ people in employment and accessibility to services. According to Batchelor (1984), HIV+ patients have been victims of job terminations and have been refused nursing and hospital services. ADA not only proscribes discrimination against these patients in medical and other public services, but it also protects HIV+ people who wish to compete for new employment or keep their present jobs. Under ADA, they need not reveal their disease to potential employers, since employers are enjoined from taking medical histories except in post-offer physical examinations (which must be administered to all people in a specific occupation). Even in the case of medical examinations, these must be related to essential job functions or to a direct threat to others in the employment situation (Turley & Beck, 1991). This direct threat could take the form of a kitchen worker's Hepatitis B, in which there is specific evidence that the worker could transmit the illness through food or kitchenware, or perhaps of a person who has poorly controlled paranoid schizophrenia in the job of police officer. HIV infection is relatively difficult to transmit, therefore, the ADA's standards offer plenty of protection for the person who is HIV+. Apparently, the only occupations which may be precluded for a person who is HIV+ are those in which there may be an occasion in which bodily fluid is exchanged. Rehabilitation counselors may perform a valuable service by advising their HIV+ clients that they are not required to respond to preemployment inquiries regarding their disease.

## Rural Clientele

The incidence of HIV infection is rapidly increasing in the nation's rural areas (Centers for Disease Control, 1992). Moreover, the reported incidence of HIV in these areas may vastly underrepresent actual cases, since many rural residents are not aware of testing sites in their

area; also, these sites may be so far from their homes that even when people are aware that there is something physically wrong with them they may still not be tested. Concerns about confidentiality may also impede testing.

HIV+ clients in rural areas have problems which are directly proportional to the rurality of the locale in which they live. The smaller the town, the more rural the residence. The fewer the jobs, services, and facilities available in the area, the more likely the HIV+ person is to be concerned with stigma (the grapevine effect in small towns) and accessible services (transportation, doctors, dentists, and other professionals) and to become fatalistic or depressed. In addition, the support systems available to these people, especially self-help groups, may be lacking because of distance or because people who are HIV+ may not be aware of each other or of these services.

*The 1990 Americans with Disabilities Act (ADA) provides protection for HIV+ people in employment and accessibility to services.*

The cultural overtones in rural areas often aggravate the problems mentioned above. First, rural people are often more religious and fundamentalist in their orientation. This may be a factor in stigmatization if the disease is interpreted as a plague from God on sinners. Second, it may add to the destruction of the person's support system if the person is rejected by family members, friends, employers, or others; this rejection may occur more frequently in conservative areas. Finally, if the person

who is HIV+ shares these same cultural beliefs and values, that person may experience commensurately more guilt and shame, with their concomitant isolation and depression.

## Women

The counseling needs of women with HIV infection will differ from those of men because of five differences between men and women:

- differences in mode of transmission;
- differences in clinical progression;
- cultural differences;
- women's reproductive capabilities; and
- women's social role of mothering.

## Mode of Transmission

By July 1992, 24,323 women had become HIV+. Of these, 50 percent acquired the virus through intravenous drugs use, while another 35 percent contracted it through heterosexual contact. The majority (61 percent) of cases involving heterosexual contact were with partners who were also intravenous drug users (IVDU's) (Centers for Disease Control, 1992).

The problems of women IDVU's are many. Typically, they have few resources and must also care for children (Wofsy, 1987). If they have a sexual partner, it is most likely that he too is an IVDU (Cohen, Hauer, & Wofsy, 1989). In addition, these women have more medical problems, including malnutrition, anemia, hepatitis, high blood pressure, diabetes, urinary tract infections, dental disease, and sexually transmitted disease (Cohen, Hauer, & Wofsy, 1989; Mondanaro, 1988). The reason many have no financial support may be due to the family of origin being sexually or physically abusive (Chaffee, 1989) or it may be due to the stigmatization that results from drug use and/or prostitution (Cohen, Hauer, & Wofsy, 1989). All of these problems lead to increased stress and lower self-esteem for drug dependent women (Mondanaro, 1987).

HIV is about 12 times more likely to be transmitted from a man to a woman than from a woman to a man (Padian,



Shiboski, & Jewell, 1990). There appear to be two factors which account for this. The first is the greater number of infected men which increases the probability that a woman's partner will be infected. The second possibility is that male-to-female transmission is more efficient. This is hypothesized to be due to the larger mucosal surface in the female genital tract (Alexander, 1990; Friedland & Klein, 1987).

Women are most typically infected in a heterosexual relationship by a drug using partner or a bisexual male (CDC, 1992). Women who have contracted HIV from a drug using partner may have many of the same economic and emotional problems as women who use intravenous drugs (Cohen, Hauer & Wofsy, 1989). Additionally, they may not feel they are at risk because they do not use drugs themselves (Karan, 1989). A different set of issues arises when a woman learns she has been infected by a partner she did not realize was bisexual. Typically there are feelings of betrayal and a questioning of her own femininity (Buckingham and Rehm, 1987).

Prostitution has also been cited as a major cause of the spread of HIV. However, the risk of HIV infection for prostitutes seems to be more a function either of their own intravenous drug use or the neglect of practicing safer sex in their personal relationships (Miller, Turner, & Moses, 1990).

## Clinical Progression

Initially, it appeared that the clinical expression of HIV/AIDS in women was similar to the expression of HIV infection in men, with the exception that women seldom develop Kaposi's sarcoma (Poole, 1988; Wofsy, 1987). Later studies (Carpenter, Mayer, Fisher, Stein, & Danforth, 1990) have suggested that there may be a different clinical course. In their study of women in Rhode Island, Carpenter et al. (1989) found that esophagitis was the AIDS identifying infection in most (38 percent) of the women. This differs from other sources (Kristal, 1986) which have shown pneumocystis pneumonia to be the

most frequent AIDS defining diagnosis. In addition, *Candida albicans* was found in 23 of the 24 women. Imam et al. (1990) have found a hierarchical, progressive pattern of *Candida* in women described in the following.

"Recurrent, often severe, vaginal candidiasis may occur in HIV-seropositive individuals with little or no suppression of CD4 or CD4/CD8.<sup>1</sup> Oral candidiasis generally develops after more marked immunosuppression, and esophageal candidiasis occurs only with severe immunocompromise" (p. 145).

The study by Carpenter, et al. (1989), also found an increased rate of chronic perianal herpes simplex virus in their subjects which may be gender related. Seropositive women also seem to be at an increased risk of human papillomavirus (a virus that causes warts) which is a precursor of cervical neoplasia (tumors of the cervix) (Sillman, Stanek, Sedlis, Rosenthal, Lanks, Buchhagen, Nicastrì, & Boyce, 1984). From this study it is hypothesized, "... that cervical lesions may represent an early clinical manifestation of HIV in women" (Ickovics & Rodin, 1992, p. 6). Given these differences, women may need very different treatment from that which has been effective for men (Carpenter et al., 1989).

There are conflicting reports on whether women die earlier after a diagnosis of AIDS. Studies by Friedland, Saltzman, Vilenò, Freeman, Schrager, and Klein (1991) and Rothenberg, Woelfel, Stoneburner, Nilberg, Parker, and Truman (1987) state that women die significantly sooner after an AIDS diagnosis than men. However, a report by Ellerbrock, Bush, Chamberland, and Oxtoby (1991) showed no significant differences in survival times between women and heterosexual males with AIDS. If there truly is a difference in survival times, it may be due to diagnosis and treatment occurring later in the disease process for women (Ickovics & Rodin, 1992). Women with HIV/AIDS may have a difficult time finding an AIDS-wise physician who is familiar with this disease in their gender (Rodin & Ickovics, 1990). Prevention efforts to this point have been geared to-

ward opportunistic infections which affect men. Since these may be different in women, the counselor may need to help the client find a physician familiar with the clinical expression of AIDS in women. The counselor may also wish to help the woman push to be included in clinical trials. This will be difficult as women traditionally are excluded from clinical trials. According to Rodin and Ickovics (1990), this is true even in animal models and they state the reasons as follows:

"Female animals and humans are often dismissed as study subjects because their normal hormonal fluctuations are seen as potentially contaminating research results. An additional explanation for women's exclusion from this research includes avoiding possible toxic exposure to women of childbearing age" (p. 1025).

A few women were included in the trials of AZT (Fischl, Richman, et al., 1987). Given the increasing number of women who are HIV-infected, it is hoped that more will be included in future studies.

## Pregnancy

It has been recommended that women who are HIV+ postpone pregnancy until more is known about the impact of the disease (Centers for Disease Control, 1986). It has also been recommended that women who are infected be informed of all reproductive options, including abortion (American College of Obstetricians and Gynecologists, 1988). The reasoning behind this is if a woman knows she is HIV+ and receives counseling about the dangers of infecting her child as well as possible increasing her own chances of developing AIDS, she will choose not to become pregnant (Sunderland, Minkoff, Handte, Moroso, & Landesman, 1992). This has not been the case in many instances (Selwyn, Carter, Schoenbaum, Robertson, Klein & Rogers, 1989; Sunderland et al., 1992). The reasons women risk having an infected baby are many. For both black and Hispanic cultures, a great value is placed on a woman's ability to reproduce. For these women, hav-



ing a child may improve their status in the community. Often, pregnancy is the one time a chemically dependent woman may feel good about herself.

For some women, a baby is the one thing they have to love that will love them back. Many times, the risk is taken so that a child is left as a legacy (Levine & Dubler, 1990). Others may have a child to replace a child lost to death or foster care. Still, for others who are asymptomatic there may be an element of denial that they have the disease (Miller, Turner, & Moses, 1990). Finally, "the birth of a child may also serve as a social bond to a continuing relationship with a Black male who, because of the scarcity of men, is a precious commodity" (Mays & Cochran, 1988, p. 953). Whether or not a pregnancy hastens the progression of a woman's HIV infection to AIDS is not known for certain. Studies by Biggar, Panwa, Minkoff, Mendes, Willoughby, Landesman, and Goedert (1989) as well as Minkoff, Nanda, Menez, and Fikrig (1987) indicate that there is an acceleration. A study by Selwyn, Schoenbaum, Davenny, Robertson, Feingold, Shulman, Mayers, Klein, Freidland, and Rogers (1989) found no acceleration of infection during pregnancy. Minkoff et al. (1987) have suggested that pregnant seropositive women are only at risk of acceleration of their disease if their CD4+ count is below 300.

The AIDS epidemic is posing a threat to the reproductive rights of women (Mantell et al., 1988). Many women are afraid that women, especially those of color, will be forced to submit to court-ordered fetal lifesaving obstetrical interventions (Kilder, Gallagher, & Parsons, 1987). Others are concerned that involuntary sterilization of infected women as well as involuntary testing of high-risk groups will be proposed (Newman, 1987).

## Mothering

Currently, 85 percent of pediatric cases of AIDS have been contracted through perinatal transmission (Center for Disease Control, 1992). These children, then, have mothers who are

HIV+. In most households it is the mother who assumes the caretaker role when a child is ill. However, in these cases the mother is often too ill to care for her children (Campbell, 1990). A summary of these women's needs relative to child care is given in the introduction to the *Women and AIDS: Clinical Resource Guide* (1987). It states:



"Women with children need child care services not only for the times they are too ill to care for their children, but for the time consuming task of dealing with a life threatening illness. In order to comply with medical care and treatment protocols, keep social service appointments, and seek mental health and support services, child care services need to be available" (p. 7).

Mothers who are chemically dependent may have even more concerns. These women may be facing legal problems because of drugs or prostitution. Many times, a spouse will leave a chemically dependent woman, who may therefore need legal help in the areas of divorce or child custody (Reed, 1988).

According to Ybarra (1991), the major needs of HIV+ mothers is help to forgive themselves and preparation for leaving their children behind. She also notes that the counselor may need to help find homes for the children.

## Minority Clientele

Counselors may have traditional problems with countertransference towards minority clients (Jones, 1987), which are compounded by the fears that counselors have with issues related to HIV+ infection (contagion, death anxiety, homophobia). According to the National Clearinghouse for Alcohol and Drug Information (1990), blacks and Hispanics make up 39 percent of all IVU-HIV+ related cases and 71 percent of all HIV+ cases among women, even though blacks and Hispanics are only 20 percent of the population. Also, counselors may misinterpret information about culturally different clients to the point that the client leaves the counseling situation or the counselor actually inflicts harm unintentionally. Minority clients also have specific medical case management needs which the counselor may encounter. Some clients who are marginally acculturated and who still depend upon traditional cultural mores may choose either to deny symptoms and their illness or to seek help from shamans rather than medical personnel. These tendencies may promote the spread of the disease within specific minority communities. Counselors who are sensitive to utilitarian ethics (the greatest good for the greatest number) may wish to consider prevention tactics in order to combat this spread.

One area which prevention-minded counselors may consider is that of sex education for ethnic people. Peterson and Marin (1988) point out that among some black men, there exists a belief that they are not at risk for HIV+ as long as they do not engage in sex with a white gay male. Briggs (1987) ascribed the increase of HIV+ in the black community to economic factors (e.g., joblessness) and Fullilove and Fullilove (1989) reported that the increase of crack-cocaine use leads to high-risk practices such as the exchange of sex for drugs or money. As was pointed out above, Mays and Cochran (1988) argued that the scarcity of eligible black men was a factor in pressuring some black women to give into unsafe sex to



maintain a relationship. Dalton (1989) points out that the African-American church, being fundamentalist and conservative, has stood in the way of AIDS education. The same author noted that many African-Americans view the AIDS epidemic as genocide aimed at blacks. Finally, Jordan (1991) has described attitudes on the part of many black women in which they are unwilling to "tell her business" outside the family and a moral imperative that she be able to handle things on her own.

The Hispanic population of the United States (including Mexican-Americans, Puerto Ricans, Cubans, and others) is seen by various researchers as having increased risk for HIV infection. Amaro (1988) noted the younger mean age of Hispanics, which means relatively more experimentation with sex and drugs. Mays and Cochran (1988) mention that their risk is one more item which is wrapped up in their culture of poverty. Ventura (1987) mentions Hispanic women's higher fertility rate and their propensity to bear children earlier and continue later than Anglo women. Other culturally-based beliefs and values in the Hispanic community which interact with the HIV epidemic are a belief in folk healers<sup>2</sup> and a fatalistic, external locus of control (Comas-Diaz, 1990); a tolerance for extramarital affairs by men (Carrier, 1985; Espin, 1985); and a reluctance to disclose private matters outside the family combined with a preference to cope by praying and/or withdrawal into day-dreaming or drug use (Nyamathi & Vasquez, 1989).

## Addicts

HIV infection interacts with two principal groups of addicts: alcoholics and intravenous drug users. Both alcohol and opiate derivatives adversely affect the body's immune system (Ferrando & Batki, 1991; Institute of Medicine, 1986), which in turn makes the body more vulnerable to HIV disease progression. Malnutrition also is a complication of alcohol and other drug addictions, which indirectly affects the immune system. An example of the price being

paid by immunosuppression is the recent rise in tuberculosis, a disease once thought to have been eradicated (Langone, 1988). Other diseases which are complications of being HIV+ interact with alcohol and drugs. These include pneumocystis carini (Langone, 1988), muscle damage and weakness, cancer (West, 1984), and neurological diseases, such as headaches, aphasia, seizures, gait disturbance, visual disturbances, incontinence, and forgetfulness (Falvo, 1991). Medical management of HIV patients who are also addicts is complicated because addicts engage in lowering inhibitions regularly (which promotes high-risk behaviors); they ignore their nutritional necessities; and they neglect treatment elements which have been prescribed by their medics.

***Counselors need to address their own feelings with regard to death and dying and isolation and their reactions to culturally different clients or homosexuals.***

Counselors who are engaged in helping addicts may encounter three problems which have arisen with the HIV virus:

The first is that of the spread of HIV through contaminated needle sharing. The corollary of this problem is that public laws and policies, which make drug paraphernalia illegal, actually promote needle sharing to avoid prosecution and safehouses as loci in which drug subcultures exist to provide these illegal items.

The second problem is the drug and alcohol interaction with human immune systems. Thus, a person who is abusing or addicted to alcohol and/or drugs is actually hastening the onset of symptoms and death by further suppressing the immune system.

The third problem is that the focus of most substance abuse counselors is on abstinence, and those life problems (work, secondary disabilities, meaning-of-life issues, etc.) which may interfere with abstinence are either seen as justification for rationalization and denial or as distractions from the main goal of abstinence. The problems most immediate for HIV sufferers may be in the areas of depression, grief, and loss, rather than addiction itself. Counselors must therefore be trained to deal with these other areas and have the ability to "change gears" as needed in order to deal with the person as a whole. It seems apparent that traditional drug and alcohol counseling and rehabilitation needs to look at abstinence as being inextricably intertwined with psychosocial sequelae of HIV infection.

## Homosexuals

Homosexuals have traditionally had the highest incidence of HIV infection than any other group, although this is rapidly changing. Two significant problem areas that gay HIV+ people may experience are those of double stigmatization and depression. The stigmatization may be experienced in interactions with friends, lovers, family, employers, professionals, and others. When turned inward, the stigmatization often is productive of exogenous depression which tends to aggravate the discrimination which being either HIV+ or gay may already pose. That is, the person joins in his or her own victimization and abuse by self-denigration. The Institute of Medicine (1986) cited a longitudinal study which compared levels of distress in homosexuals and found that those who suffered from AIDS-related complex (ARC) had greater psychological problems.



## Treatment

According to Coates, Temoshok, and Mandel (1984), social support has a direct positive effect on the person's health. Thus, self-help or support groups are essential for the person with HIV infection to fulfill educational, moral support, spiritual, and/or religious needs. These groups can counteract negative reactions, especially those which are related to withdrawal. The release from sympathetic nervous system reactions involved in anger, or those involved with the parasympathetic system such as depression, have improved immunological functioning (Smith, 1989). And finally, support groups may, through mutual support and encouragement, prevent life-negating acts involved in self-neglect and suicide. This fact alone points out the importance and urgency of support groups. Male AIDS patients between the ages of 20 and 59 are 36 times more likely to commit suicide than other men (Marzuk, Turney, Gross, Tarcliff, Morgan, Mann, & Hsu, 1988).

Counseling and therapy need to be modified to accommodate HIV patients. First of all, counselors need to address their own feelings with regard to death and dying and isolation and their reactions to culturally different clients or homosexuals. Kelly (1985) states that counselors should examine their own beliefs about God, death, and the afterlife because these beliefs may have a powerful effect on the course of counseling, such as in the tendency to blame the victim for a religious transgression. Counselor denial or rejection can be detected by clients, which then can deepen their depression and aggravate their self-esteem problems, not to mention increase their drop-out rate.

Counselors in substance abuse treatment centers need to attend to the way HIV patients use drugs and alcohol. The sudden removal of them may also deprive the client of a coping mechanism; besides, the client may be much more motivated to deal with grief issues rather than the need to abstain (Batki, Sorensen, Faltz, & Madover, 1988). Also, Stall, Watters, and Case

(1989) ask how treatment personnel can demand abstinence of a client when they are showing them safe ways to sterilize their injection equipment.

Methadone maintenance programs for IVDU-HIV patients have several advantages: Their retention rate is higher than outpatient detox and residential therapeutic communities (Ferrando & Batki, 1991); these programs obviate the need for unsafe injection; methadone clinics may also treat the client for their other needs—social, psychiatric, and vocational—besides their addiction ones (Ferrando & Batki, 1991); and methadone is not as harmful as street heroin in suppressing the immune system (Ferrando & Batki, 1991).

Because of the stigma and isolation that women with AIDS encounter, the counselor working with women who have AIDS may also be a case manager and a support system. Stigma affects women in a variety of ways:


- HIV infection has long been identified as a man's disease, thus giving infected women a profound sense of isolation;
- because seropositive women are such a diverse group, there is little peer support available;
- if the woman has been infected by a male, she faces the stigma associated with his behavior; and
- a woman always faces stigma if she does something that seemed harmful to the developing fetus during pregnancy (*Women and AIDS: Clinical Resource Guide*, 1987).

Counseling a seropositive woman may progress through three phases:

The first occurs immediately after the diagnosis when the counselor may need to work with the client on concerns such as anger and denial.

The second phase presents the woman with three tasks: getting on with life, facing and grieving the losses, and coping with the unpredictability of the disease (*Women and AIDS: Clinical Resource Guide*, 1987). The counselor may wish to use strategies such as assertiveness training, teaching coping skills, thought stopping, cognitive reframing, relaxation, and meditation to assist the client with these tasks (Hoff-

man, 1991). In addition, the counselor may wish to help the client develop or strengthen her support system.

The final phase of the counseling process occurs as the client nears death. The tasks at this time may involve facing fears of death or the dying process, pain management, and supporting those left behind. "Interventions must be designed to work with the entire support system by honoring the patient's wishes and facilitating the dying process for all involved" (*Women and AIDS: Clinical Resource Guide*, 1987, p. 10). 

## Notes

1. CD4 and CD8 are T-cell subgroups; these cells are analyzed in the evaluation of the health of the immune system.
2. Folk healers refer to practitioners of spiritual healing; in Mexico, for example, practitioners of "brujeria" and in Puerto Rico, "santeria." Some Hispanic people may go to folk healers instead of, or prior to, a medical physician.

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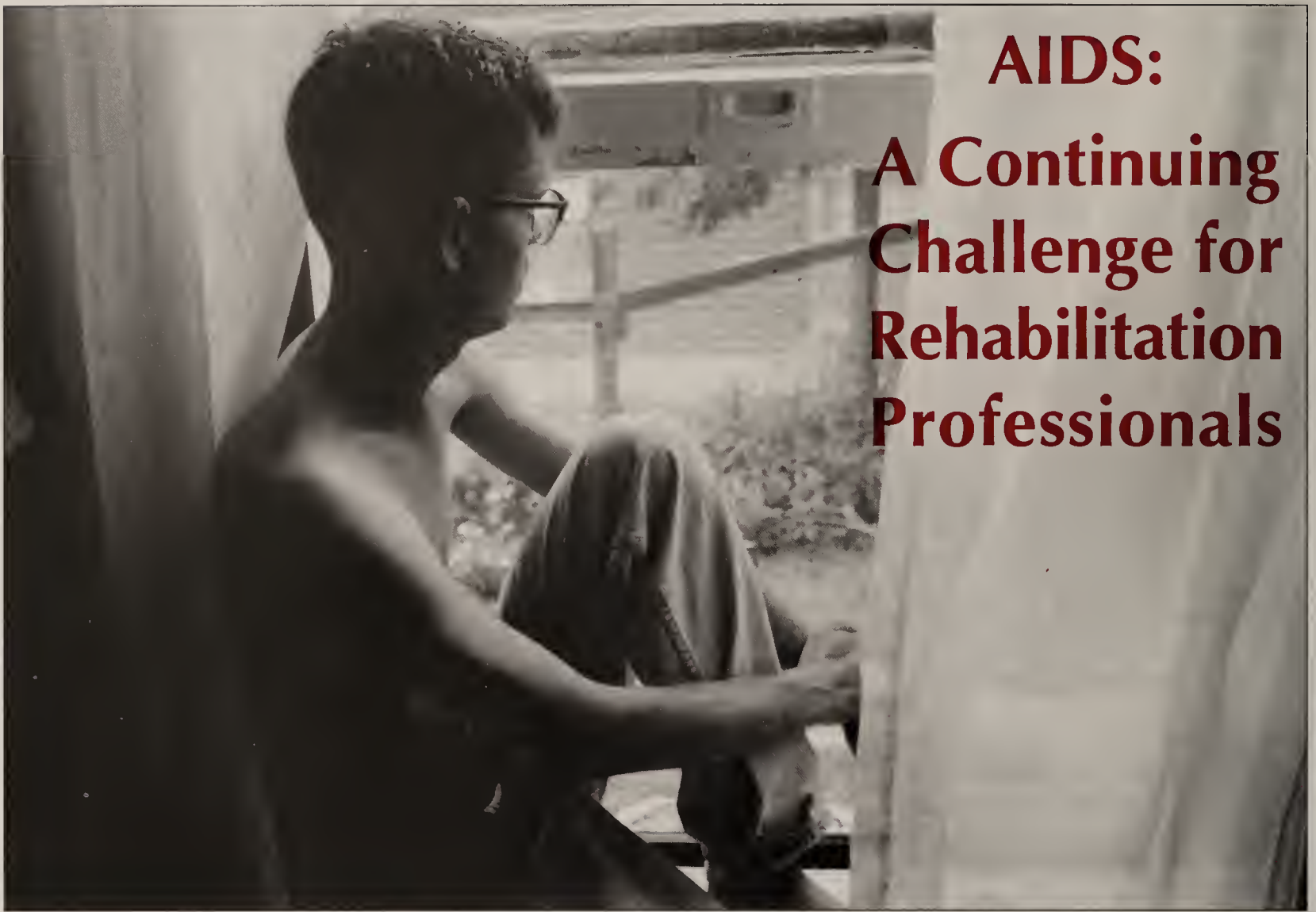
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# AIDS: A Continuing Challenge for Rehabilitation Professionals

***AIDS, as a disease and disability, is a vital concern to rehabilitation professionals because of its economic, medical, social, ethical, and political impact on human resources. This article presents an overview of the implications of AIDS for the rehabilitation community and challenges rehabilitation personnel to remain involved in seeking viable solutions.***

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With the AIDS epidemic universally recognized as one of the major challenges of our time, rehabilitation professionals have a mandate to not only participate in implementing strategies, but also to function as leaders for the nation as it responds to the problem of AIDS. This mandate is supported by Canon 9 of the Code of Professional Ethics for Rehabilitation Counselors, which states: "Rehabilitation Counselors shall establish and maintain their professional competencies at such a level that their clients receive the benefit of the highest quality of services the profession is capable of offering" (McCrone, 1988, p. 102).

In addition, as new information emerges the definition of the two key

concepts of HIV positive (or HIV+) and AIDS continues to change.

The Teacher Education Resource Manual (1991) provides some useful medical information regarding HIV as reported by Keeling. The resultant HIV definition is:

"The Human Immunodeficiency Virus (HIV) causes a chronic, progressive, immunologic deficiency disease with a spectrum of manifestations. Taken together, these manifestations comprise the continuum of HIV disease. This continuum consists of a series of identifiable and predictable phases, or stages, that follow one another in sequence. People with HIV disease move along this continuum at varying rates, depending upon the influence of a variety of factors" (p. 4).

Four major stages/phases of the HIV disease are cited by Keeling as:

- Acute (primary) HIV Disease;



- Chronic Asymptomatic HIV Disease;
- Chronic Symptomatic HIV Disease; and
- Advanced (severe) Disease (AIDS).

The U.S. Department of Education (1987) defines AIDS (acquired immune deficiency syndrome) as:

"A disease caused by a virus that destroys a person's defenses against infections. These defenses are known as the immune system. The AIDS virus, known as human immunodeficiency virus, or HIV, can so weaken a person's immune system that he or she cannot fight off even mild infections and eventually becomes vulnerable to life-threatening infections and cancers" (p. 1).

It is incumbent upon the rehabilitation professional to continuously seek the current definition of these two concepts and information on their implications for service delivery.

The number of people who are HIV+ and who have AIDS is significant. As of February 1992, 213,641 cases were reported in the United States, with 138,395 cases resulting in death. Currently, the 40-75 percent of people with AIDS who are receiving the treatment AZT have a 35 percent reduction in the risk of death (*Morbidity and Mortality Weekly Report*, 1990) and the promise of new hope. The number of people in the United States who are infected with the AIDS virus (HIV+) but have not developed the disease is now estimated at 1 million (Center for Disease Control, 1992). Thus, Wong, Allen, and Moore (1988) note:

"... as the disease is brought under better medical care and as the prognosis improves for persons with AIDS, the rehabilitation professional will be called upon to provide rehabilitative and restorative services for this group. This will require a broad and diverse number of counselor skills. Some of the major tasks faced by all rehabilitation personnel who serve persons with AIDS will be overcoming the social, personal and institutional barriers that confront this group" (p. 39).

Rehabilitation professionals also have a responsibility to serve as advocates in indicating that AIDS is not a moral

issue, but a health (life/death) issue of human resources in the community. A major role for rehabilitation professionals is to provide employers with education about the disease of AIDS, its future impact on the workforce, and how to adjust to new medical conditions and needs of all employees.

The need for rehabilitation educators and other professionals to be involved in the eradication of AIDS is also unquestionable. Rehabilitation professionals are in a unique position to provide education to employers and also to students who will then practice the profession of rehabilitation counseling and work with businesses and people who are living with AIDS.

***As people who are HIV+ are living longer, the involvement of rehabilitation professionals becomes more important.***

The impact of the rehabilitation educator and professional is manifold:

- they have a powerful opportunity to impact on attitudes;
- they are in a position to provide educational information that can reduce the individual's risk of becoming HIV+; and
- educators will be contributing to a better quality of life for persons living with AIDS by their sensitive, enlightened involvement with students who will then be working as rehabilitation professionals.

As people who are HIV+ are living longer, the involvement of rehabilitation professionals becomes more important. Equally important is the need for educators to reflect on the philosophical foundations of rehabilitation counseling that focus on the quality of

life for people with disabilities. Clearly, rehabilitation educators and professionals have a role to play that has far-reaching, positive implications.

## Challenges and Recommendations

All of the HIV/AIDS literature reflects that counselors must be aware of their own attitudes and biases. Counselors, educators and others involved in working with the community need to develop a knowledge base that has the potential to be revised quickly, establish linkages with individuals in related disciplines, learn from persons living with AIDS, and advocate for empowerment for all people with disabilities.

Not only is AIDS a health issue, but it touches on all major sources involved in quality of life issues. Specifically, AIDS has the potential to cause people to explore their values, beliefs, sexual behaviors, views of death/dying, relationship development, fears, hopes, dreams, religion, and more. As powerful as the ramifications of AIDS are, many people feel that they are not at risk because they are not homosexual males living in San Francisco or an African-American intravenous drug user living in New York. AIDS is no longer someone else's problem. No one is immune from its human, economic, medical, social, ethical, and political impact.

Awareness of the need to provide services to people with AIDS within public vocational rehabilitation programs is not well established in our society. It is critical that public vocational rehabilitation examine its personnel, professional training, allocation of resources, policies, counseling process, and educational programs to learn what has been and can be accomplished to best meet the needs of people with AIDS.

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Some inherent problems within the rehabilitation community are lack of knowledge of psychosocial issues and discomfort about meeting the needs of clients with AIDS. Little research has been disseminated to alleviate this dilemma. An additional problem is focused on individual values and ideas pertaining to people with AIDS. Another problem is that many rehabilitation workers are only superficially aware of the employment discrimination experienced by people with AIDS.

A major dilemma encountered by the rehabilitation professional was presented by Feist (1991) when she reported that:

"Often they [rehabilitation professionals] are faced with an ethical dilemma when clients refuse to inform those with whom they come in contact of their disease. Although confidentiality is crucial in the code of ethics, . . . many practitioners are unsure of when confidentiality should be breached" (p. 225).

Another challenge is the lack of a systematic set of practices on how to serve as an educator to employees or as a vocational advocate for the consumer with AIDS. Overall, rehabilitation's response to these cited problems and related issues is the essence of the challenge. Everyone needs to be involved.

Similarly, Haney (1988) viewed many of the potential psychosocial consequences of AIDS as disconnections: disconnections from the past, present, and future; from loved ones; and from ways of defining ourselves, such as job activities, capabilities, skills, and physical appearance. "Finally, AIDS may lead to a disconnection from things many of us take for granted, such as a sense of power and control over our lives, hopes, dreams, and aspirations. This further exacerbates the sense of isolation, alienation, and aloneness that people with AIDS experience" (p. 251).

Among the approaches for empowering people who have AIDS to effectively cope with disconnections is through the perceived sense of power and control one experiences by contributing to the community through the workforce. Providing a sense of purpose and direction in extending the

Table 1 Selected References and Resources on AIDS	
1.	<i>AIDS: Changing the rules</i> (1987). Washington, D.C. (Video) WETA-TV, Educational Activities, P.O. Box 2626, Washington, DC 20013. Telephone: (703) 998-2709 or toll free at 1-800-845-3000
2.	<i>AIDS Information for People of Color</i> . San Francisco AIDS Foundation.
3.	<i>AIDS Today</i> —A medical case management quarterly. K. Thorn, Thorn Publications, 7657 Winnetka Avenue, Suite 629, Canoga Park, CA 91306.
4.	<i>American Psychologist</i> (1988). Special issue: Psychology and AIDS. 43, 11.
5.	Center for Disease Control (1990, March 13). <i>HIV-AIDS surveillance report</i> . Atlanta, GA: Author.
6.	Corthell, D.W., & Oliverio, M. (1989). <i>Vocational rehabilitation services to persons with HIV (AIDS)</i> . University of Wisconsin-Stout: Research and Training Center.
7.	<i>Drug users: Do not share needles</i> . Health Education Resource Organization (HERO). (301) 945-AIDS
8.	<i>Gay Mens' Health Crisis</i> . (212) 807-6655
9.	<i>Hispanics AIDS Forum</i> 853 Broadway, Suite 2007, New York, NY 10003. (212) 870-1902 or 870-1864
10.	Kain, C.D. (1989) (Ed.). <i>No longer immune: A counselor's guide to AIDS</i> . Alexandria, VA: AACD
11.	Kiester, E. (1990). <i>AIDS &amp; vision loss</i> . New York: American Foundation for the Blind.
12.	<i>Minority Task Force on AIDS</i> . (212) 749-1214
13.	<i>Mothers of AIDS Patients</i> . (619) 234-3232
14.	<i>National AIDS Information Clearinghouse</i> P.O. Box 6003, Rockville, MD 20850, 1-800-458-5231; TTY/TDD: 1-800-243-7012.
15.	<i>National AIDS Information line</i> : 1-800-342-AIDS (24 hours per day). The Spanish Hotline: 1-800-344-7432. Hearing Impaired: 1-800-AIDS-TTY.
16.	Reichert, D.A., & MacGuffie, R.A. (1988). AIDS: An overview for rehabilitation counselors. <i>Journal of Applied Rehabilitation Counseling</i> , 19, 2, 34-37.
17.	U.S. Public Health— <i>American Red Cross</i> .
18.	U.S. Public Health Service—Center for Disease Control—What about AIDS testing? What you should know about AIDS. How you won't get AIDS.
19.	Wong, H., Allen, H.A., & Moore, J. (1988). AIDS: Dynamics and rehabilitation concerns. <i>Journal of Applied Rehabilitation Counseling</i> , 19, 3, 37-41.

quality of life for the consumer is fundamental. Establishing a sense of power and control is an essential strategy in empowering the person with AIDS to live life fully. The acquisition of power by the individual is a cornerstone in the practice of rehabilitation and underscores the essence of the public vocational rehabilitation process. Rehabilitation professionals cannot

circumvent their responsibilities to work with people who have AIDS or are HIV+. Regardless of the nature of the disability, our first priority is focused on the individual.

Haney (1988) further noted in reporting from the Advisory Committee of People with AIDS that the beginning of helping people with AIDS not to view themselves as victims is by not



buying into the notion yourself. "To label us as 'victims' . . . implies defeat and we are only occasionally 'patients,' which implies passivity, helplessness, and dependence upon the care of others. We are 'people with AIDS'" (p. 253).

Continuing with his theme of "disconnection," Haney (1988) proposes an additional caution regarding the significance of the role of hope for everyone involved with people living with AIDS:

"AIDS is truly devastating in its effect of disconnecting the person with AIDS from things that have a lot of meaning. For example, many people who have AIDS become unable to work. This has the potential of destroying a sense of productivity and contribution and disconnecting the person with AIDS from a sense of self-worth. Furthermore, this disconnects the person with AIDS from a sense of future, something to work toward and look forward to. Persons with AIDS need assistance to realize a sense of purpose and meaning, whether through job rehabilitation, assistance redefining self-worth, or help finding a flexible job so the person with AIDS can work when feeling energetic" (p. 252).

Overall, rehabilitation professionals must continue to examine their own inherent values and attitudes to ensure that they are not unconsciously projecting an insensitivity for the needs and rights of all people with disabilities, including people with AIDS.

Knowledge through education is the solution to supporting the underlying rehabilitation values of a "belief in all people's worth and dignity, belief in the individual's capacity for growth and self-determination, acceptance of the uniqueness of the individual, and the importance of self-help and client participation" (Haney, 1988 p. 253).

The need for assertive action by rehabilitation professionals and educators and their peers is clear:

First, there is a need for the development of training materials dealing with issues concerning AIDS. These materials could include tapes, films, case studies, and attitude scales, in addition to counseling alternatives and strategies.

Second, there is the need for professionals in related disciplines to provide accurate, up-to-date information to rehabilitation professionals. An interdisciplinary team approach would include nursing and related medical professionals, legal personnel, government representatives, sociologists, and all types of professionals involved in empowering people with AIDS.

Third, internship placements in rehabilitation agencies where the rehabilitation student will encounter persons living with AIDS must be considered. Helping to reduce the fear of being infected with the HIV virus and attitude modification in specific work settings is another assertive action.

***The need for assertive action by rehabilitation professionals and educators and their peers is clear.***

Valid research which relates to all areas of living with AIDS is needed and can be supported through the use of master's theses and doctoral dissertations. Finally, professional ethics necessitate that rehabilitation educators and counselors vigorously share knowledge and provide information to their students and communities about what is perhaps this generation's most frightening illness.

We need to experiment with a variety of methodologies for presenting AIDS education to rehabilitation professionals and counselors, students, employers, and to the community at large. It is suggested that strategies include lectures, discussions, values clarifications, videos, readings, conferences, workshops, computer programs, panels comprised of persons living with AIDS,

and any other creative approaches that can be identified.

Backer (1987) suggests that rehabilitation has a role both in the healthcare cost containment and return-to-work aspects of dealing with the AIDS crisis in the workplace. "Rehabilitation professionals can contribute their knowledge of effective rehabilitation techniques and various technologies that can help workers with AIDS cope with the demands of work. Knowledge of rehabilitation principles and programs can guide policies and practices in the workplace regarding AIDS, including attitude-changing education for management and other workers" (p. 39).

## Summary

As people providing AIDS education, we need to be aware of the pitfalls or limitations of AIDS education. One is that people may be defensive about discussing this sensitive topic. Thus, as educators, we must be nondefensive and prepared to deal with the questioning of assumptions.


It is critical that information be targeted so that it is age appropriate, that it is multiculturally appropriate, that we avoid discussion of people's religion, and that we not blame an individual for his or her sexual orientation.

The best hope for prevention rests on effective public information and education. Rehabilitation professionals have a vital role to play in this particular area and in disseminating the belief that AIDS can be prevented through awareness of behaviors that place people at risk for HIV infection. A selected set of resources is provided in Table 1 to assist in this area.

We must keep in mind that information and data is constantly changing and that we must therefore employ effective methods to remain current. This reinforces the tremendous need to approach AIDS education and prevention from a holistic, multicultural perspective. The Americans with Disabilities Act (ADA), for example, is a new tool that, if we fully understand and exploit its possibilities, can provide a whole new dimension to our



mission regarding people who have AIDS. Also, we have not begun to address many of the unique approaches we can apply toward the specific disability/disabilities of each individual. This is an area that warrants our constant attention.

If we do not accept the role demanded of us by the AIDS crisis, rehabilitation professionals and educators will become part of the problem rather than an important part of its solution. Clearly, we can be proud of our successes throughout the history of American rehabilitation in resolving complex disability issues, and the AIDS epidemic requires not less but more of a proactive stance. Our responsibility as rehabilitation professionals and advocates for individuals with disabilities directs us to focus on meeting the challenges of awareness, support, quality of life, and independence for people with AIDS. 

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## All U.S. Workers to Get Instruction in 'AIDS 101'

David Brown  
Washington Post Staff Writer

Over the next year, all federal workers will get basic instruction about human immunodeficiency virus (HIV) and AIDS, and managers will also be taught to adjust workplace rules to accommodate people who are infected with HIV.

"We need to set an example... I want all of you to take this as seriously as I do," President Clinton told Cabinet members who met at the White House yesterday, where the plan was announced.

Employees of the military, and federal hospital and prison systems, are now taught how to avoid HIV infection, and what to do should they become infected, said Kristine Gebbie, the administration's national AIDS policy coordinator. Until

now, however, such instruction was not required elsewhere in the government.

"We want everyone to have what I call 'AIDS 101,'" said Gebbie, who attended the Cabinet meeting. "It might be as short as a one-hour session, or it might be two or three hours broken into several sessions. We are leaving room for the agencies to be flexible." Some form of instruction, however, will be required in every agency.

"I don't think the president is going to give them the option of saying they can't take the time for this," she said.

Some agencies may choose to design their own "courses," and use government employees as instructors. Other agencies may hire existing AIDS education charities. Departments are expected to pay for the plan with their existing budgets.

There are about 2 million civilian and postal employees in the federal government, but no estimates of how many

are HIV-positive. Nationally, about 1 in 250 Americans is infected with the virus.

Managers will be expected to make some concessions for people with the AIDS virus. This might include changing work hours as an infected person becomes more ill, or allowing absences so an employee can take part in a clinical trial. The supervisors' instruction should also cover such topics as employees' attitudes toward infected coworkers, and confidentiality in the workplace.

Persons with HIV infection are protected from discrimination by the Americans with Disabilities Act. Gebbie said the new flexibility may require changes in federal personnel rules.

The AIDS education may begin as soon as December.

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Charles E. Young

One of life's more difficult experiences is having to stand by helplessly as an associate dies of a terminal illness. The situation becomes much more difficult to bear when this person is a friend, a colleague, and one of your favorite vocational rehabilitation (VR) counselors, a favorite because of his ability to relate to people: to clients, fellow staff members, and even to you, the state agency administrator. Watching such a friend and co-worker die of AIDS complications makes you more keenly aware of the issues associated with HIV. Likewise, personal involvement with HIV issues brings home the unique perspective of the individual affected, his family and friends, and for you, his employer.

Having had this experience, as an employer who has dealt with the reality of HIV in the workplace, I feel a special obligation to contribute, in every way possible, to the improvement of services available to people with HIV.

Because good management always sets the direction and tone for delivering services in any agency, rehabilitation agency administrators and program managers should take the lead in developing a comprehensive and informed response to HIV. A definitive agency policy on HIV along with the provision of appropriate staff training should be at the core of such a response and would

# HIV and Rehabilitation Management

signal management's commitment to serving eligible people with HIV.

Educating consumers and others about eligibility for rehabilitation services is one of management's perennial tasks. As most readers of this journal know, basic vocational rehabilitation services provided under the Rehabilitation Act can only be offered to people with a physical or mental disability which is an impediment to employment. VR services must be required to achieve an employment outcome. Further, each eligibility decision must be made on an individual basis, not for groups of people with a given disability. Unfortunately, advocates often mistakenly assume that a person who has a certain severe disability is automatically eligible for vocational rehabilitation services. This assumption is not true. Advocates frequently confuse *eligibility* for vocational rehabilitation with *entitlement* to programs such as special education for youth. VR can offer needed services only to those HIV infected persons who are eligible for VR services. We need to take the lead in helping these clients become eligible. An educational process needs to be initiated to assure that advocates of persons with HIV understand the VR eligibility criteria and service delivery potential. People with HIV and their advocates need to be educated on the following basic VR eligibility criteria:

- there must be a physical or mental disability;
- this disability must be an impediment to employment for the individual; and
- the individual must require VR services to achieve an employment outcome. Where employment is not a goal, agencies should not overlook the use of independent living resources.

Rehabilitation managers have numerous considerations when developing a policy in response to HIV. This could take the form of an umbrella policy on life-threatening illnesses in general or an HIV-specific policy. The policy would spell out when such individuals might be eligible for traditional rehabilitation services, facilities, programs, or independent living services. The agency policy might address such issues as:

- confidentiality;
- availability of comparable services and benefits;
- extent of agency medical payments;
- prohibition on purchase of experimental drugs and treatment;
- providing equipment and services for people who may not be medically stable;
- using independent living services as a resource; and
- establishing categories of risk classification for staff in all routine and reasonably anticipated job-related tasks (including identifying those tasks which might expose staff or clients to body fluids, such as daily living skills instruction in cooking or instruction in insulin injection for blind clients).

Developing standard operating procedures (SOP's) for work tasks which might cause exposure to body fluids may be considered. These could include mandatory work practices and use of protective equipment. Unfortunately, this may well be an issue of employer liability and could even creep into future union contracts.

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Mr. Young is Administrator of the Oregon Commission for the Blind and Past President of the Council of State Administrators of Vocational Rehabilitation (CSAVR).



Foremost in any policy should be respect for the individual and his/her rights. Confidentiality of all health records must be maintained. People with HIV, whether clients or staff, may be physically disabled and are therefore protected by Section 504 of the Rehabilitation Act with regard to employment. They are also protected by the Americans with Disabilities Act (ADA).

## Marketing this Service

VR, which has been a traditional resource to employers, can take a leading role in disseminating information to break down barriers to employment for individuals with HIV. Agencies can establish employer advisory groups and offer technical assistance or educational programs at the worksite to help educate employees about co-workers with HIV. This effort could assist employers and their work force to be more receptive to working with these individuals. However, the VR agency or facility needs a clear policy on how it will treat employees with HIV in order to give confidence and credibility to agency staff making such educational presentations to the public.

## Agency Educational Programs

An education program for all employees is advised and would help implement an agency's policy. The rapid spread of HIV to all segments of society necessitates that all employees learn and practice appropriate infection-control procedures to assure workplace safety.

Education programs would accomplish several objectives:

- provide employees with the information they need to make informed choices to reduce their risk of exposure;
- share information and skills training for infection control and prevention; and
- promote a nondiscriminatory, compassionate response to co-workers and clients with HIV.

In addition, management can ensure that agency medical consultants and the state disability determination unit are also educated on this critical issue. VR

agencies may wish to offer their training to other rehabilitation facilities, Client Assistance Projects (CAP's), private rehabilitation providers, independent living centers/programs, and other sources of rehabilitation services in the state.

Rehabilitation managers can greatly improve their services to eligible people with HIV by working with other organizations and service providers. Developing cooperative agreements and initiatives with these groups—which should include state health departments and organizations formed specifically to assist people with HIV—is important. Since many people with HIV might benefit from independent living services, agreements with these service providers should be made in advance of referral. Outreach procedures could be developed to encourage referral of potentially eligible clients.

## Management Commitment

Rehabilitation managers can demonstrate a commitment to serving those with HIV in many ways. They can develop a case coding for tracking when HIV is a factor in eligibility determination. They can direct outreach efforts to encourage people with disabilities and HIV to apply for services. They can be creative in identifying possible sources of rehabilitation services. As an example, VR professionals should consider using independent living programs to provide services. VR agencies serving blind people frequently have people with HIV referred to them who need training in alternative techniques of performing everyday household activities. Many of these agencies have used independent living services to maximize their clients' abilities to live at home with dignity.

It is important for rehabilitation managers to monitor caseload assignments to prevent overloading staff who have a high rate of success or who volunteer or specialize in serving persons with HIV. "Burnout" is reportedly a real problem for staff confronted with caseloads of people with HIV. The appropriateness of such specialized caseloads should be dictated by the incidence of HIV in a


specific geographic area, agency size, state population, and the need to develop highly trained liaisons with other public and private service providers.

Some staff, overly concerned about "unsuccessful closures," may tend to avoid serving clients who have HIV. Even worse, some employees may refuse to work with co-workers or clients who have HIV; counseling and perhaps disciplinary measures may be needed to remedy these situations.

To stay current with developments in services to people with HIV staff also require ongoing training. Additionally, training in coping with issues of death and dying could be offered to direct service providers.

It is also important for rehabilitation managers to consistently evaluate the rewards and recognition they provide to all their staff, to ensure that service providers' needs are met with the same care as are the needs of the people they serve. Because people with HIV can benefit from VR services, they should be offered the same opportunities to work that our society endeavors to make available to people with other disabilities.

Yet, we also need to be aware of the possibility that eventually some people with HIV may become too ill to contribute effectively. I have seen a good counselor eventually become too ill to perform his duties and I have seen how his co-workers were required to carry too much of his workload. At such a point, VR managers may have to intervene, so that everyone concerned will be able to deal with this highly emotionally-charged situation.

I know that my experience is not unique. Many rehabilitation agencies, facilities, and independent living centers have had employees with HIV and have served clients with HIV as a primary or secondary disability. Unfortunately, it appears that state agencies and facilities will continue to be confronted with the issue of HIV in future years. It is therefore imperative that management address this issue promptly and explicitly. 



# NEW PUBLICATIONS AND FILMS

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## **NO PITY: People with Disabilities Forging a New Civil Rights Movement.**

Joseph P. Shapiro. *Times Books, New York, NY 10022.* 372 pages. Hardcover, \$25.

For the last 30 years, the disability rights movement has been working hard to dispel the myths and stereotypes about people with disabilities that have made them a hidden, misunderstood minority, often routinely deprived of the basic life choices that most of us take for granted.

This book brings to life the issues, the politics, and the people that have shaped the disability rights movement over the last three decades, from its inception at Berkeley in the 1960's, through the enactment of the Americans with Disabilities Act, to the issues that will face people with disabilities in the future. Nearly a dozen pages in this book describe the historical role of Judith E. Heumann, newly appointed Assistant Secretary of the Office of Special Education and Rehabilitative Services, U.S. Department of Education. (See cover II of this issue of *American Rehabilitation*.)

The author tells many of the personal stories that he has uncovered in his 5 years of indepth reporting. For example, Larry McAfee, a quadriplegic, wanted to end his life rather than cope with a system that denied him the right to work or make his own decisions. Even more discouraging than the healthcare system's inability to assist Mr. McAfee was the fact that most Americans supported his decision to commit suicide, assuming that a quadriplegic's life was not worth living. Nancy Cleaveland, a 52-year-old woman with retardation, was forced to go to court to win the right to live with her boyfriend.

The author also includes his own, first-hand experience in helping Jim, a friend with mental retardation, gain freedom from the Minnesota mental institution where he had spent most of his life. Jim's experience is a prime example of what is wrong and, occasionally, right with America's social service system.

## **Productive Living Strategies for People with AIDS.**

Jerry A. Johnson, editor. Michael Pizzi, guest editor. *The Haworth Press, Inc., 10 Alice Street, Binghamton, NY 13904-1580.* 227 pages. Hardcover, \$29.95; softcover, \$17.95.

From the time of diagnosis, people with HIV disease often encounter challenges in occupational functioning, including problems in mobility, strength, and coordinated movement; pain; difficulty in caring for one's personal needs or performing in work, school, home, and community environments; and limitations in engaging in routine activities. Experts from the fields of rehabilitation medicine, nursing, social work, and occupational and physical therapy have created a unique resource filled with information on improving quality of living through rehabilitation. These experts address a vast and diverse set of topics, including the medical and psychosocial aspects of adults and children with HIV, rehabilitation needs of HIV-infected children and their caregivers, AIDS in the prison system, spiritual and cultural aspects, day treatment program development, human values, and gay grief. Case examples, intervention strategies, and program development are emphasized so that both the layperson and healthcare professional can share in the vision of rehabilitation for people with HIV and AIDS.

## **The Biology of AIDS. Second Edition.**

Hung Fan, Ross F. Connor, and Luis P. Villarreal. *Jones and Bartlett Publishers, Inc., 20 Park Plaza, Boston, MA 02116-9990.* 176 pages. Softcover, \$25.

This text attempts to provide the reader with a conceptual framework of the issues surrounding AIDS by confronting those difficulties which challenge science and society to respond appropriately. This second edition includes the latest epidemiological data, discussion of compound Q., and the Eliza Assay.

Subjects covered include: An Overview of AIDS, Concepts of Infectious Disease and a History of Epidemics, The Immune System, Virology and Human Immunodeficiency Virus, Clinical Manifestations of AIDS, Modes of HIV Transmission and Personal Risk Factors, and Future Directions in Combating AIDS.

## **AIDS: The Making of a Chronic Disease.**

Elizabeth Fee and Daniel M. Fox, editors. *University of California Press, 2120 Berkeley, CA 94720.* 436 pages. Softcover, \$15; hardcover, \$45.

The essays in this book explore the ramifications of AIDS as a chronic killer disease, more and more like heart disease, cancer, and stroke in the demands it makes on the individual body and the body politic. The contributors come from a wide variety of professions and communities; some are activists, most are committed chroniclers of the social history of the disease.

Sections are devoted to "The Virus and its Publics" (Part I), "Law, Ethics, and Public Policy" (Part II), "Affected Populations" (Part III), and "International Perspectives" (Part IV). Part III



includes a particularly cautionary essay, "The First City: HIV Among Intravenous Drug Users in New York City," which provides an object lesson for cities all over the world where drug users are still relatively HIV-negative: "Don't do what New York did; do what New York didn't do."

#### **Marijuana & AIDS.**

R.C. Randall. Galen Press, P.O. Box 53318, Temple Heights Station, Washington, DC 20009. 183 pages. Softcover, \$12.95 plus \$3.50 postage and handling.

Marijuana can dramatically improve the quality of life for people with AIDS (PWA's) and many are illegally using the drug for medical purposes, according to this book, which documents marijuana's utility in treating symptoms of AIDS and the side effects of commonly used AIDS drugs like AZT.

This book tells the story of four PWA's who successfully petitioned the Federal Government for legal access to marijuana and also provides the following:

- valuable information on how to legally obtain marijuana from the Food and Drug Administration (FDA);
- answers to commonly asked questions about marijuana's medical use;
- a complete discussion of marijuana's effects on the immune system;
- marijuana v. Marinol, the synthetic "pot pill" available by perscription; and
- a complete index and glossary of terms.

#### **AIDS and Accusation. Haiti and the Geography of Blame.**

Paul Farmer. University of California Press, 2120 Berkeley, CA 94720. 338 pages. Softcover, \$13.

This study traces the introduction of AIDS into Haiti; provides an indepth overview of Haiti's history and political economy, with an emphasis on European domination and United States influence; explores the experiences and understanding of the disease by Haitians; and profiles the personal experiences of the first Haitians to contract AIDS.

The book is divided into five parts: Part I, Misfortunes Without Number; Part II, AIDS comes to a Haitian Village; Part III, The Exotic and the Mundane: HIV in Haiti; Part IV, AIDS, History, Political Economy; and Part V, AIDS and Accusation.

#### **Making Disability: Exploring the Social Transformation of Human Variaton.**

Paul C. Higgins. Charles C. Thomas, Publisher, 2600 South First Street, Springfield, IL 62794-9265. 292 pages. Hardcover, \$49.75.

Starting with the premise that "We make disability," and that disability is not a natural quality of people or their individual traits, the author focuses on some important, interrelated social means through which we make disability and explores how we might "make it more successfully."

Chapters examine the concepts of "Framing Disability," "Manufacturing Disability," "Depicting Disability," "Interacting and Identifying Disability," "Experiencing Disability," "Servicing Disability," "Policy(ing) Disability," "Managing Disability," and "Remaking Disability."

#### **Progress in Clinical Neurologic Trials. Volume 1: Amyotrophic Lateral Sclerosis.**

F. Clifford Rose, M.D., editor. Demos Publications, Inc., 386 Park Ave. South, Ste. #201, New York, NY 10016. 238 pages. Hardcover, \$69.95.

The first in a series of monographs on metodological problems in clinical trials of neurological disorders, this volume on amyotrophic lateral sclerosis (which now has no cure) is intended for persons attempting to perform clinical trials and for those who need to assess therapeutic claims.

#### **Adaptive Technologies for Learning and Work Environments.**

Joseph J. Lazzaro. American Library Association, Books Marketing Manager, 50 East Huron St., Chicago, IL 60611. 251 pages. Softcover, \$35.00. ALA member price, \$31.50 Toll free telephone: 1-800-545-2433, Ext. 2424.

Starting with the personal computer, the author describes representative peripherals successful in reducing barriers to people with disabilities in public institutions, draws on the universal mainstream technology, and tells how to mate it with adaptive technology to allow the user with disabilities to work side by side with the nondisabled user.

The text provides a brief overview of adaptive technology and discusses how to install and integrate adaptive equipment and how to train consumers in its use.

The book also includes an index of federal regulations, disability oriented publications, state-based technical assistance programs, and agencies which provide services to people with disabilities.

#### **Standards For Agency Management and Service Delivery.**

The Council on Accreditation of Services for Families and Children, 520 Eighth Avenue, Suite 2202B, New York, NY 10018. \$50 in print form (\$40 for 10 or more or for members of Council sponsor organizations) and \$60 (\$50, members) on IBM-compatible disks.

This revised edition offers social service and mental health agencies a comprehensive guide to the principles essential to excellence in the delivery of human services. In addition to generic organizational and service delivery requirements, the publication details specialized requirements in more than 40 types of organized care settings.

The standards were compiled through a process of consensus building among practitioners, researchers, academics, managers and representatives of national organizations and help to identify strengths and areas for improvement and serve as an objective reference for developing a long-range strategic plan.

The standards contain a glossary of the most commonly used professional terms, plus a comprehensive index for locating references to primary concepts.

The publication could be an invaluable resource for social service and mental health administrators, public health officials, foundation staff, per-



sons representing corporate and federated giving programs, and client and advocacy groups.

The Council on Accreditation is a national, nonprofit accrediting body which provides an independent, objective process of agency review in the field of mental health and human services.

### **The Economic Consequences of Traumatic Spinal Cord Injury.**

Monroe Berkowitz, Ph.D., Carol Harvey, Ph.D., Carolyn Greene, and Sven E. Wilson. Demos Publications, Inc., 386 Park Ave. South, Ste. #201, New York, NY 10016. 202 pages. Hardcover, \$64.95.

This document is a seminal piece of work in the field of the economic and socioeconomic costs of spinal cord injury (SCI). It provides a highly detailed and comprehensive accounting of the direct and indirect costs of SCI, the prevalence of traumatic SCI, and its impact on service provision. The lead author, Dr. Monroe Berkowitz, is highly regarded as an expert on the economics of rehabilitation.

A representative group of SCI persons of all ages and with varying dates of injury were contacted for this survey. Each person was interviewed at length so that as much as possible could be learned about the economic costs associated with SCI.

### **Migraine**

Oliver Sacks. University of California Press, 2120 Berkeley Way, Berkeley, CA 94720 or 50 E. 42nd St., Rm. 513, New York, NY 10017. 362 pages. Softcover, \$13; hardcover \$30.

The author has brought together virtually all the features of modern knowledge on the subject of migraine, with special emphasis on what has been learned in the past 20 years. This revised and expanded edition contains additional case histories, new findings, and practical information on treatment. The original edition was published in 1970.

## **AIDS Policies and Education**

*Continued from page 18*

8. Kastner, T., Grosz, J., Harvey, D.C., Hopkins, K.M., Murphy, A., Nathanson, R., & Rudigier, A.F. (1991) Human immunodeficiency virus and developmental disabilities: A leader's guide for a workshop. [Grant No. 90DD015 from the Administration on Developmental Disabilities, Office of Human Development Services, U.S. Department of Health & Human Services]. American Association of University Affiliated Programs for Persons with Developmental Disabilities.

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## **RSA Opens Its Bulletin Board System**

The Rehabilitation Services Administration's electronic Bulletin Board System (RSA-BBS) is now open for public access by computer and modem.

RSA is expanding the use of its dedicated BBS to provide on-line, downloadable copies of all Information Memoranda, Policy Directives, approved RSA Manual Chapters, etc. These will be available in WordPerfect format, ASCII, and compressed ASCII (if necessary), excluding any attachments that may not be readily available in electronic medium. Use of the RSA-BBS facilitates the distribution of such material and provides it in computer readable format for individuals with disabilities who might have difficulty with hard copy versions.

At this time toll-free access is not available. Set your modem for N-8-1 (Parity = None, Data = 8, Stop = 1). We request that users with slow modems only use the 202-205-5574 access number.

### **ACCESS:**

1200/2400bps—(202) 205-5574;  
9600/14400bps—(202) 401-6147.



## Assistant Secretary

*Continued from Inside cover page*

tion Act so that people with disabilities will have greater opportunities to achieve an independent lifestyle. And I will work to fully implement the Americans with Disabilities Act in my role as assistant secretary.

"I will have accomplished my goals if we stop seeing the needs of people with disabilities as being special and different. I want to work with all of you to ensure that we are part of the total fabric of our country. We have many laws on the books. Now we must enforce the letter and spirit of these laws."

Ms. Heumann is responsible for a budget of more than \$5.25 billion and a staff of 411 people and she now directs programs that serve nearly 6 million children, youths, and adults with disabilities.

For the past 10 years, Ms. Heumann has been based in Oakland, California, at the World Institute on Disability, which she co-founded in 1983. Considered a global "think tank," WID was the first public policy, research, and training organization to focus primarily on issues affecting disabled people.

From 1975-82, Ms. Heumann was deputy director of the world's first independent living center, located in Berkeley, California. In that capacity she helped draft state and federal legislation, resulting in the creation of more than 200 independent living centers nationwide.

Previously, Ms. Heumann was a legislative assistant to then Senator Harrison Williams, D-N.J., who chaired the Senate Labor and Public Welfare Committee. In that capacity she helped develop legislation that became the Education for All Handicapped Children Act (P.L. 94-142) and Section 504 of the Rehabilitation Act of 1973. Ms. Heumann was featured on the cover of the April-May-June 1987 issue of *American Rehabilitation* as one of the prime forces behind development of Section 504 and its regulations.

Ms. Heumann, who contracted polio at age 18 months, became involved in disability issues after graduating from



## HIV and AIDS

### Resource Guide Available for Special Education Teachers

A resource guide to help educators teach special education students about HIV prevention and AIDS is available through The Council for Exceptional Children (CEC) and the Association for the Advancement of Health Education (AAHE).

This resource guide was published as part of AAHE's 5-year project, "HIV Infection and AIDS Prevention Education: Interdisciplinary, Multicultural Approaches for Students and Teachers," which is aimed at preventing the transmission of the human immunodeficiency virus (HIV) by promoting HIV prevention and AIDS education in comprehensive school health programs. The cooperative agreement was funded by the Division for Adolescent School Health, National Center for Chronic Disease Prevention and Health Promotion of the Centers for Disease Control (CDC).

Copies of *HIV Prevention and AIDS Education: Resources for Special Educators* may be obtained by contacting Ginger Katz, education specialist, The Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091-1589, or by calling (703) 264-9451.

The Council for Exceptional Children is the only professional organization dedicated to improving the quality of education for all exceptional children and youth, both handicapped and gifted. Its over 54,000 members include teachers, administrators, teacher educators, students, support services professionals, and parents. Special divisions within the organization focus on the education of students with varying exceptionalities: giftedness, mental retardation, learning disabilities, visual impairments, communication impairments, physical disabilities, and behavior disorders.

The mission of the Association for the Advancement of Health Education is to advance health by encouraging, supporting, and assisting health professionals concerned with health promotion through education and other systematic strategies. A professional membership organization representing 10,000 health educators and health promotion specialists, AAHE is an organization of the American Alliance for Health, Physical Education, Recreation and Dance, headquartered in Reston, VA.



Long Island University in 1969, when she applied for a teaching position in the New York City school system. She was denied a job because of her disability and subsequently sued the board of education to become the first wheelchair user to teach in the New York City public school system.

Ms. Heumann has served on the boards of various organizations, received numerous awards, and is inter-

nationally known as a speaker on disability issues.

In 1975, she received a master's degree in public health administration from the University of California at Berkeley.

She married Jorge Pineda, a certified public accountant, formerly of Mexico City, in a civil ceremony on May 30, 1992, and in a Jewish religious ceremony on August 16, 1992.



**Terry Carlton**  
**1943–1993**

This issue of American Rehabilitation is dedicated to Terry Carlton, who died September 9 of complications due to AIDS. Mr. Carlton is the lead author of the article on page 2 and co-author of the article on page 20 of this issue.

—*The Editor*



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# AMERICAN Summer 1994 REHABILITATION

## Special Projects

Part 1 of 2





# Fredric K. Schroeder, Commissioner Rehabilitation Services Administration



*Dr. Schroeder reviews documents with Special Assistant Susan K. Benbow.*

**O**n July 18, Fredric K. Schroeder became the ninth commissioner of the Rehabilitation Services Administration (RSA) and the twelfth commissioner of the federal rehabilitation program. He was nominated by President Clinton on May 12, confirmed by the U.S. Senate on July 1, and sworn into office on July 18.

As the new RSA Commissioner, Dr. Schroeder will administer a \$2.2 billion program that annually provides services to more than 1 million people with disabilities.

Dr. Schroeder's commitment to people with disabilities comes from personal experience. He was born in Lima, Peru, in 1957. His father, who had studied in the United States, believed that his sons would have greater opportunities if they were to leave Peru. When the future RSA Commissioner was only 19 months old, he and his brother were adopted by Florence Schroeder, a Professor of Child Growth and Development at the University of New Mexico. At the age of 7, Fredric Schroeder

became legally blind from a little known condition called Stevens-Johnson Syndrome.

Although he was not totally blind at this point, his vision decreased over the ensuing 9 years until the age of 16 when he became totally blind. While in school, he attempted to function using what little vision he had. The results were serious gaps in his education and a badly bruised self-esteem. Those subjects in which he could not see well enough to compete were generally waived. These included virtually all reading assignments, spelling, most mathematics, and science. His primary education consisted of what he could pick up by sitting in class.

After graduating from high school, he wanted to immediately enroll in college but he lacked the confidence and skills necessary to compete effectively. It was at this point that Dr. Schroeder first became involved in the National Federation of the Blind. With help from the federation, he obtained necessary

training in the use of the white cane, Braille reading and writing, and the other skills necessary to function competitively. More importantly, the federation gave him encouragement and a belief that he could set high goals and reach them through persistence and hard work. He entered college in January 1975, and 2 and 1/2 years later he earned a baccalaureate degree with dual majors in psychology and elementary education. To accomplish this feat Dr. Schroeder had to carry course loads ranging from 19-24 credit hours per semester as well as attend summer classes. Graduating magna cum laude from San Francisco State University in 1977, he continued his education and in 15 months earned a master's degree from the same institution. At the age of 21 with a master's degree in the education of blind children, he began looking for work.

In spite of his excellent grades and strong recommendations, he found that school districts were reluctant to inter-

*Continued on page 44*

# AMERICAN REHABILITATION

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Summer 1994

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Cover Photo: Anne Lustfeldt, a traumatic brain injury survivor, has several part-time jobs and has been nominated for the 1994 Fairfax County (Virginia) Volunteer of the Year award. (Photo by David Galen Photography. See related story on p. 20.)

U.S. DEPARTMENT OF EDUCATION  
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OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES  
Judith E. Heumann, Assistant Secretary  
REHABILITATION SERVICES ADMINISTRATION  
Fredric K. Schroeder, Commissioner  
Frank Romano, Editor

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# Enhancing Employment Outcomes for Individuals with Serious and Persistent Mental Illnesses

*In an attempt to improve services to people with serious and persistent mental illnesses, we examined the role of the mental health rehabilitation facility and its relationship with Missouri Division of Vocational Rehabilitation (DVR). We noted that a substantial number of our participants who achieved employment had indeed been former vocational rehabilitation (VR) consumers but that the VR effort was often not properly acknowledged. This occurred frequently because, in many instances, the individual's case had been closed prior to the achievement of employment. The other side of this coin is that a significant number of VR consumers with serious and persistent mental illnesses for whom competitive work was the expected outcome failed to achieve it within the VR contract time period.*

Robert B. Harvey, Ed.M, CRC,  
LCSW

Since the Indepence Center in St. Louis opened in 1981, its members and staff have sought ways to promote employment and simplify the path for those who seek it. Many of us have suspected that systemic changes as well as individual program improvements would be needed to positively influence the achievement of employment.

With respect to program improvements, the center structured its services so that access to employment was an integral part of the milieu. Paid work experiences in regular places of businesses were made easily accessible for participants through an expanded transitional employment program. A significant detour from traditional vocational program design was taken by assuming that the participant's willingness to try to work is the best indicator of readiness to work. This assumption, and the others outlined in the *conceptual frame* below, have far-reaching programmatic consequences. They affect daily programming and, more importantly, the relationships between the staff and the people served.

In addition, a substantial program improvement was made through a grant from the Missouri DVR, through which additional job development staff were hired to locate and capture job opportunities.

With respect to systemic concerns, we made certain assumptions about the people with whom we worked and the state-federal VR program system. Some individuals with long-term mental illnesses have special needs that complicate and frustrate the VR refer-

ral process. The ongoing and often volatile and labile nature of chronic mental illnesses requires, we posited, a special system that responds quickly to rehabilitation opportunities. The VR system, in contrast, is perceived by many consumers as cumbersome and/or unresponsive. This perception is, we believe, the result of dissonance between the system structure and the special needs of the target population.

The current VR system reimburses community rehabilitation programs on a person-by-person, fee-for-service basis. When a person with disability is authorized to attend a facility, the facility is paid only when that person attends and only as progress toward goals is positive. During the assessment (vocational evaluation) phase, the facility is paid to render a judgement about the participant's current and future needs. That judgement determines, in part, which, if any, services are to be provided.

Why question this system? As we have already noted, many competitively employed VR consumers do not pass the evaluation or drop out or otherwise fail to achieve employment within the VR contract period.

VR services are time limited and structured accordingly. The VR consumer must make use of and be able to benefit from the services purchased on his or her behalf *within the contractual or extended contractual timeframe*. Yet, the field's ability to accurately predict both *if* and *when* a person with this disability will benefit from vocational services appears to be problematic. For the most part, the field has attempted to resolve the problem by seeking ways to improve the professional's ability to predict the future more accurately. There are underlying assumptions to this struc-





*Independence Center's West Pine House.*

ture: that each consumer's course is linear and that, for the employment-ready consumer, there is little fluctuation in the individual's level of functioning. These assumptions deserve investigation. If, in fact, the journey towards employment is not linear, but is better depicted as a sine wave-like line that

gradually climbs the vertical axis and if, in fact, the level of functioning of consumers follows a similar pattern, then the programs we offer and the structure of the VR system that supports these programs can and should be examined.

An alternative demonstration was undertaken to examine what happens if

a community rehabilitation program is compensated on a *level of service* (LOS) basis rather than on a consumer-by-consumer basis. A level of service system requires the provider to serve a minimum number of eligible individuals for a flat, annual fee. A provider serving more persons with disability than the minimum does so at its own expense, but can use the number served to request a higher level the following year (along with an increase in annual flat fee). Such a system would make it unnecessary to predict both if and when a particular person will benefit from VR services. Rather, it is based on predicting the future behavior of a group of consumers. Such a system would:

- enable the facility to provide services that better match the needs of a group of consumers,
- reduce the staff time spent in formulating predictions for individuals (and, therefore, increase rehabilitation time),
- permit a more accurate assessment over time, and
- permit participation by a broader range of persons with more severe disabilities.

Further, while time-limited vocational services would be provided to the group, individuals in the group should benefit from a more forgiving timeframe with cost saving benefits to VR. In order to justify this approach, VR must have a valid expectation of a predetermined minimum number of people with severe disabilities to be served, a minimum number of consumers with successful employment outcomes, and a predetermined, average cost per person.

A project was undertaken to determine if a level of service approach (concurrent with a psychosocial rehabilitation program support base) would enable the achievement of successful employment outcomes by individuals who had, heretofore, not been able to go to or sustain work.

---

*Mr. Harvey is Executive Director of the Independence Center, St. Louis, Missouri.*



**Table 1. Categories and VR Status<sup>1</sup> of Disabled Individuals Served by the Project and Their Employment Outcomes**

	A	B	C	D	E
Category and VR Status	Number of Participants	Employed 60 days or more	Employed less than 60 day	Of Column C Still Employed as of 9/93	Of Column C Not Employed as of 9/93
Never a VR Consumer	55	13 (24%)	42 (76%)	4 (7%)	38 (69%)
Former VR Consumer	125	52 (42%)	73 (58%)	5 (4%)	68 (54%)
Closed Status 26	26	14 (54%)	12 (46%)	0 (0%)	12 (46%)
Closed Status 28/30	27	6 (22%)	21 (78%)	4 (15%)	17 (63%)
Declared Ineligible Status 08	72	32 (44%)	40 (56%)	1 (1%)	39 (54%)
Current VR Consumer	56	30 (54%)	26 (46%)	3 (5%)	23 (41%)
Applicant Status 02/06	31	15 (48%)	16 (52%)	1 (3%)	15 (48%)
Active Status 14-24	25	15(60%)	10 (40%)	2 (8%)	8 (32%)
<b>TOTAL</b>	<b>236</b>	<b>95 (40%)</b>	<b>141 (60%)</b>	<b>12 (5%)</b>	<b>129 (55%)</b>

## Discussion

Two hundred and thirty-six people with serious and persistent mental illnesses were served; of these, 72 (31 percent) had previously been declared ineligible, most often because of noncompliance. Of the 72 people declared ineligible (Status 08), 32 (44 percent) achieved employment and held it for more than 60 days. Ninety-five (40 percent) of the total people served achieved employment for more than 60 days, and an additional 12 (5 percent) failed to make the 60-day cut-off because they ran out of year. In other words, the 12 in column D are likely to complete 60 days bringing the number of people who *would have been eligible for a Status 26 Closure* to 45 percent. Of the 55 people who never applied for VR services, 13 (24 percent) achieved employment for more than 60 days and an additional 4 (7 percent) are likely to achieve it, for a total of 17, or 31 percent.

## Conceptual Frame

This project has three major suppositions upon which it is based:

1. *That there is a window of opportunity for each person with a disability during which VR services will be most useful and effective.*

As described above, the field's ability to predict when the window will be open is questionable. The flexibility and rapid response needed to offer appropriate vocational services when they will be most effective may be best

achieved by designing services for groups of consumers. Individuals within the group will be able to take advantage of the services as their own individual situations warrant.

2. *That the journey to employment is more successful with a series of "little steps."*

By building a service system with a gradual rather than a "graduation" philosophy, more people are afforded the opportunity to experience work as a natural and integral part of their rehabilitation course. Feelings of competence and self-confidence can be ob-

***Many mental health professionals view the VR system as rigid and inflexible. Many VR professionals cannot understand why mental health professionals expect the VR system to pay for services that are not vocational.***

**Table 2. The Likely VR Status Under the Existing Fee-For-Service System of the 236 people Served and Their Employment Outcomes**

Employment Information	Number of Participants	Likely VR Status (S) of Project Participants								
		S-08	S-28	S-02	S-06	S-14 to 18	S-20	S-22	S-24	S-26
Employed less than 60 days	141	39	9	25	46	10	0	0	12	0
Employed 60 or more days	95	0	0	0	0	18	12	13	11	41
Total	236	39	9	25	46	28	12	13	23	41

### Discussion:

Please note that our best estimate of the likely VR status of project participants served had they been served under the existing fee-for-service system shows that 41 people would have achieved a Status 26 closure (by working more than 60 days). This compares to 95 people who actually worked 60 days or more and could have been closed under a level of service system. By itself, this is a dramatic increase. Forty-one people comprise 17 percent of the population while 95 comprise 40 percent, more than twice as many.

Taken together, the data indicate that even in the first year under a level of service approach more people with serious and persistent mental illnesses are served and more of them could be claimed by the VR system as successful closures. As the project gathers more experience, the employment of participants will be tracked and recorded. Table I shows that 26 former VR consumers who had been closed Status 26 and later lost their employment had since sought vocational services from the center. It is interesting to note that only two of these individuals achieved employment for 60 days. It may well be that although they had previously retained employment for 60 days, these persons never actually achieved the stable employment they require. Despite their 60-day employment, their prior closure may have been pre-mature. Such a situation is not an unusual one for the target population. The level of service approach may actually permit such individuals to have a number of work experiences which, cumulatively, will better prepare them for a longer lasting vocational and community adjustment.

### Financial Analysis

A premise behind this grant proposal is that a level of service approach will be cost effective and will generate better employment results. In order to examine the fiscal impact of a level of service approach, we first had to examine the number of months during which services were provided. After that, we had to examine the costs *as they would have been incurred* if VR had chosen to fund project participants using the existing fee-for-service payment system.

tained without the concomitant fear of failure from which so many persons with disabilities shrink.

3. *That human progress is linear only from a distant perspective and that the rehabilitation course must permit intermittent lateral and circular moves for some consumers.*

This belief is, perhaps, singularly important in understanding the intent of this project. It lies at the heart of the traditional friction between the worlds of vocational rehabilitation and mental health. Many mental health professionals view the VR system as rigid and in-

flexible. Many VR professionals cannot understand why mental health professionals expect the VR system to pay for services that are not vocational. Providing services on a level of service basis should allow maximum flexibility to the individual's rehabilitation course, while, at the same time, assuring VR that employment is the outcome for which it is paying. Under such a system, a facility's LOS agreement would be adjusted periodically based on performance. That is, a facility that failed to demonstrate that it met the expected level of service

to persons with severe disabilities and/or failed to achieve the requisite number of successful employment outcomes would have its financial contract reduced for the next period.

Such a system might also provide an incentive to community rehabilitation programs to increase the number of people with severe disabilities it serves.

The project's objectives are to:

- serve a minimum of 300 people severely disabled by psychiatric illnesses in a 3-year period,



**Table 3. The Estimated Number of Months in Which VR Services Would Have Been Consumed**

(The numbers are estimates, because there is no way of knowing with certainty if a VR counselor would have contracted for services for all available months.)

Status	Number of Participants	Less than 4	4-6	7-12
06	71	36 (51%)	11 (15%)	24 (34%)
14-18	28	11 (39%)	5 (18%)	12 (43%)
20	12	0	0	12 (100%)
22	13	0	1 (8%)	12 (92%)
24	23	1 (4%)	4 (17%)	18 (78%)
08	39	2 (5%)	3 (8%)	34 (87%)
28	9	0	4 (44%)	5 (56%)
26	41	0	1 (2%)	40 (98%)
Total	236	50 (21%)	29 (12%)	157 (67%)

### Discussion:

Of the 236 participants, 50 were served less than 4 months, 28 from 4 to 6 months, and the rest from 7 to 12 months. As project time is accumulated, the distribution will certainly change. It is interesting to note that 40 of the 41 individuals who would have been closed Status 26 spent between 7 and 12 months receiving services.

- achieve successful employment outcomes for a minimum of 150 people,
- document the course of each project participant,
- demonstrate the rehabilitation efficacy of the level of service approach, and
- analyze the cost benefit of the level of service approach.

For purposes of this project, applicants at Independence Center who are willing to try to go to work are selected as participants. Each person's VR history is determined (i.e., never a consumer; former consumer, etc.).

### Project Results

The results of the first year's experience are presented in the tables accompanying this article. No final conclusions should be drawn, however, until a complete analysis is made. It is hoped that the data will be examined critically by wary and skeptical people.

Table I describes the categories and VR status<sup>1</sup> of persons served and their employment outcomes. Table II presents the likely VR status *under the existing fee-for-service system* of the people served and their employment outcomes. Table III shows the estimated number of months in which VR services would have been consumed. (The numbers are estimates because there is no way of knowing with certainty if a VR counselor would have contracted for services for all available months.) Table IV estimates VR costs under the existing fee-for-service system for work adjustment evaluation (WAE). Table V describes the probable cost under the existing system for providing supported employment (SE) services. All clients with 4 weeks or more of project time available are assumed to have had a WAE. Only clients who have been placed for 4 weeks or more are assumed to be funded for SE.

### Summary

Although only 1 year of data are available, it appears likely that statistically significant outcomes will be documented. A level of service funding

**Table 4. VR Cost Estimates Under the Existing Fee-For-Service System for Work Adjustment Evaluation (WAE)**

(The grantee's WAE rate is \$395 for a 4-week period.)

Participants	Status	Cost
52	06	20,540
27	18	10,665
12	20	4,740
13	22	5,135
23	24	9,085
34	08	13,430
9	28	3,555
41	26	16,195
TOTAL	211	\$83,345

### Discussion:

The 211 participants who had 4 weeks available for WAE would have cost the VR agency \$83,345 under the fee-for-service system, had they all been accepted by VR.

**Table 5. The Probable Cost Under the Existing System for Providing Supported Employment (SE) Services**

(The grantee's current SE rate is \$170 per week. We have made the decision that no more than 16 weeks of SE would have been requested from the VR agency despite the fact that more weeks of support are available.)

End Status	Number of Participants	Number of Weeks	Cost (at \$170 per person per week)	Totals
18*	14	16	\$38,080	
"	3	12	6,120	
"	2	8	2,720	
"	6	4	4,080	
Total (18)	25			\$ 51,000
20	12	16	32,640	32,640
22	13	16	35,360	35,360
24*	5	12	10,200	
"	4	8	5,440	
"	6	4	4,080	
Total (24)	15			19,720
26	41	16	111,520	111,520
28*	2	8	2,720	
"	2	4	1,360	
Total (28)	4			4,080
Grand Total SE	110			\$254,320
Total SE + WAE	211		\$ 83,345	\$337,665

\* An individual must have at least 4 weeks available to be counted in a status or must be a current VR consumer who is in that status.

### Discussion:

Of the 236 project participants served during the first 12 project months, 211 had sufficient time for a 4-week WAE. One hundred and ten participants were placed into employment for a minimum of 4 weeks and were therefore considered eligible for SE services. Had the VR agency contracted for all of the participants, a total outlay of \$337,665 would have been made.

While each facility has different costs, it makes sense under a level of service approach to speculate and suggest an annual per person fee. Please note that this fee would apply regardless if the individual spent 1 day in the facility or 260 days. For the sake of argument, let us assign a \$1,000 per person annual fee. Under such an agreement, the cost to the VR agency would have been \$236,000 (a \$101,000 savings). The cost per successful placement (95 achieved employment for 60 days or more) is \$2,484. This compares favorably with current costs. (For fiscal year 1993 Missouri estimated cost per Status 26 placement was \$3,700.) Perhaps more important, however, is the indication that more people with serious and persistent mental illnesses have an opportunity to benefit from VR services under the LOS approach. This is important because some number of these can be expected to achieve employment in the succeeding year.

As the project continues, we look forward to reporting on the long-term vocational and community adjustment of project participants and how the availability of extended services (at no additional costs to the VR agency) influences long-term adjustment.


Project participants' wages averaged \$4.51/hour (range= \$4.25—\$9.00). Using this average wage and multiplying times the number of weeks each participant worked, we show estimated earnings of \$277,000 for the period. This number is almost 2.5 times the amount of federal funds awarded for the project period and larger by \$41,000 than our fictional level of service contract!



approach may merit further investigation and testing. There are serious concerns, however, about such an approach. The facility and the VR agency must be able to agree upon reasonable and challenging goals. In comparing facility programs one against another, weightings for severity of disability must be established.

Finally, a careful look at the project suggests that the role of the VR counselor may require re-evaluation. Because the rehabilitation facilities will be assuming some of the roles previously played by the VR counselor, the counselor is free to invent and discover new roles. The author has believed for some time that many rehabilitation facilities across the country would benefit from knowledgeable VR consultants who would:

- monitor levels and quality of service;
- consult on the Americans with Disabilities Act and other regulatory issues;
- assist small facilities with budgeting and fiscal reports;
- suggest program modifications if employment or other targets are not met;
- become principle advocates for persons with disabilities; and
- become a resource for facility management.

These are only a few of the new roles VR counselors might assume. If these thoughts have merit, the curriculum for training of rehabilitation counselors in the future will require modification and expansion. 

The author wishes to acknowledge the efforts of Timothy G. Lalk, MA, who compiled the data, and Sara Asmussen, Ph.D., who made it comprehensible.

### Note

1. Status classifications in the rehabilitation caseload system, coded in even numbers, signify progress and decisions points in the VR process. The caseload statuses, if fully applied, are as follows:

**Status 02—Applicant:** As soon as an individual signs a document requesting VR services, he or she is placed

into Status 02 and is designated as an applicant. While in Status 02, sufficient information is developed to make a determination of eligibility (Status 10) or ineligibility (Status 08) for VR services, or a decision is made to place the individual in extended evaluation (Status 06) prior to making this determination.

**Status 06—Extended evaluation:** An applicant is placed into this status when a rehabilitation counselor certifies the need to provide certain services to help in determining whether the individual can benefit from the full range of rehabilitation services in terms of an employment outcome. Applicants leaving this status will be moved to Status 10 (eligible for VR, services will begin without delay) or closed from Status 08 (not eligible/not accepted for VR) within the 18-month period allowed to complete the eligibility determination.

**Status 08—Closed not accepted/ineligible for VR:** This status is used to identify persons determined ineligible or who are otherwise not accepted for VR services, whether closed from the applicant status (Status 02) or extended evaluation (Status 06).

**Status 10—Individualized Written Rehabilitation Program (IWRP) development:** While in this status, an assessment of the rehabilitation needs of the individual is completed to provide a basis for the formulation of the IWRP. The individual remains in this status until the rehabilitation program is written and approved.

**Status 12—IWRP completed:** After the IWRP has been written and approved, the applicant is placed into Status 12 until services have been actually initiated.

**Status 14—Counseling and guidance only:** This status is used for those individuals having an approved program which outlines counseling, guidance, and placement as the only services required to prepare the individual for employment.

**Status 16—Physical or mental restoration:** Individuals receiving any physical or mental restoration services (e.g., surgery, psychiatric treatment, fitted

with an artificial appliance) are placed into this status until services are completed or terminated.

**Status 18—Training:** This status is used to identify persons who are receiving academic, business, vocational, on-the-job, or personal and vocational adjustment training.

**Status 20—Ready for employment:** A case is placed into this status when the individual has completed preparation for employment and is ready to accept a job, or has been placed into, but has not yet begun, employment.

**Status 22—In employment:** When an individual has been prepared for, placed in, and begun employment, his or her case is placed into Status 22. The person must be observed in this status for a minimum of 60 days before the case can be closed rehabilitated (Status 26).

**Status 24—Service interrupted:** A case is placed in this status if services are interrupted while the individual is in Status 14, 16, 18, 20, or 22.

**Status 26—Rehabilitated:** Cases closed as rehabilitated must, as a minimum, (1) have been declared eligible for services, (2) have received appropriate diagnostic and related services, (3) have had a program for VR services formulated, (4) have completed the program, (5) have been provided counseling, and (6) have been determined to be suitably employed for a minimum of 60 days.

**Status 28—Closed for other reasons after an IWRP is initiated:** Cases closed into this category from Statuses 14 through 24 must have met criteria (1), (2), and (3) of Status 26 (above); and at least one of the services provided for by the IWRP must have been initiated, but, for some reason, one or more of criteria (4), (5), and (6) in Status 26 were not met.

**Status 30—Closed other reasons before IWRP initiated:** Cases placed into Status 30 are those which, although accepted for VR services, did not progress to the point that rehabilitation services were actually initiated under a rehabilitation plan (closures from Statuses 10 and 12).



# Functional Assessment Services for Transition, Education, and Rehabilitation: PROJECT FASTER

*Assessment data should serve as the cornerstone of the rehabilitation process, guiding the provision of service offerings. Numerous studies, however, document that the results of psychometric instruments (e.g., IQ and personality tests) and traditional vocational evaluation procedures (e.g., work samples) have little relationship to actual rehabilitation performance of persons with special needs (Frey, 1984). As an alternative, functional assessment methods (Halpern & Fuhrer, 1984) that focus on the actual skills and capacities of the individual have been recommended. In the first section of this article, we discuss the rationale for functional assessment procedures to rehabilitation and present a conceptual model of these procedures. In the second section, we describe a model demonstration project that was funded in the fall of 1993 by the Rehabilitation Services Administration (RSA) to develop and provide functional assessment services for adolescents and adults with cognitive disabilities at an existing assessment facility: Project FASTER (Functional Assessment Services for Transition, Education, and Rehabilitation) (Bullis, 1993).*

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People have been assessed for almost 100 years through "traditional" intelligence, personality, and neurological instruments and procedures (Gould, 1979; Sundberg, 1977). Historically, these types of assessments have been used primarily for classifying individuals as belonging to or not be-

longing to specific groups (e.g., possessing a specific condition or not) or for determining the individual's eligibility for a certain program. Controversy exists, however, over the relationship of data from these traditional instruments to actual behaviors (McClelland, 1973). Of specific concern to the rehabilitation field is the relevance of the results from traditional assessment procedures to the employment, education, community living strengths, and needs and preferences of people with disabilities (Halpern & Fuhrer, 1984; Dowdy, Smith, & Nowell 1992).

This subject is significant, as assessment data should serve to base judgments regarding eligibility for rehabilitation programs and to plan the individual's services. The relevance of traditional intelligence, personality, and neuropsychological instruments and their respective results to the pragmatic educational, work, and community adjustment focus of rehabilitation programs is unclear at best, and may be totally unrelated to the rehabilitation process (e.g., What does an IQ score say about a person's potential to perform a particular job? What does the performance on scales 1, 2, and 3 of the MMPI say about their potential to learn how to live independently?) (Bullis & Foss, 1986; Bullis, Nishioka-Evans, Fredericks, & Davis, 1993; Bullis & Reiman, 1992; Cobb, 1983; Cobb & Lakin, 1985; Frey, 1984; Halpern & Furher, 1984; Hursh & Kerns, 1988; Porter & Stodden, 1986).

To illustrate, Cohen and Anthony (1984) reviewed the psychiatric literature on the relationship of psychometric data to rehabilitation outcomes for persons with mental and emotional disorders. They concluded the following:

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- Measures of psychiatric symptoms do *not* predict vocational rehabilitation (VR) outcome.

- The psychiatric diagnosis does *not* predict VR outcome.

- Measures of psychiatric symptoms do *not* correlate with the psychiatrically disabled person's skills.

- Measures of skills *do* predict VR outcomes.

The need for a functional assessment approach tied directly to the rehabilitation process also was made clear in a paper by the Berkeley Planning Associates (1989) on the rehabilitation of persons with learning disabilities (LD). They reported that, for this population, an effective assessment process is one that both establishes a diagnosis *and* provides practical information about consumer strengths and limitations that can be used in vocational goal-setting and service planning. A simple recommendation of more testing is not warranted, because at present the vast majority of counselors are dissatisfied with the diagnostic reports they receive on LD clients since they often do not help with establishing a clear diagnosis and rarely contribute to effective service planning. Similar conclusions have been reached for persons who are deaf (Bullis & Reiman, 1992), those with mental retardation (Stodden, Ianacone, Boone, & Bisconer, 1987), and persons with antisocial behavioral disorders (Bullis et al., 1993).

In response to the need to gather pragmatic data related to rehabilitation, vocational evaluation procedures are widely used. Vocational evaluation (Pruitt, 1976) has been defined as:

"A comprehensive process that systematically uses work, real or simulated, as the focal point for assessment and vocational exploration, the purpose of which is to assist individuals in vocational development. Vocational evaluation incorporates medical, psychological, social, vocational, educational, cultural, and economic data in the attainment of the goals of the evaluation process" (Vocational Evaluation and Work Adjustment Association, 1975, p.86).

This type of evaluation typically is implemented within a rehabilitation facility or vocational evaluation center during a specific period of time (e.g., 4–6 weeks). While vocational evaluation should employ multiple assessment tools (including psychometric instruments and situational assessments), the assessment tools paired most often with vocational evaluation are the commercially available work sample (e.g., *Singer Vocational Evaluation System*, *McCarron-Dial Work Evaluation System*, the *Tower System*) or locally developed work samples that are designed to represent jobs available in communities. These instruments represent analogue interpretations of work environments and their demands (VEWAA–CARF *Vocational Evaluation and Work Adjustment Standards*, 1975). For example, a cubicle with a particular type of job (welding) may comprise part of a work sample system.

As these instruments reflect—at least at face value—the requirements of "real" jobs and vocational settings, there is intuitive appeal to their use. Unfortunately, the psychometric properties of these instruments are generally poor (Frey, 1984; DeStefano, 1987). Results from these assessments tend to provide only static data on an individual, as they are difficult to use in a longitudinal manner to document learning, growth, and/or maturation (Sitlington, Brolin, Clark, & Vacanti, 1985). Finally, several studies demonstrate that results from these types of instruments have little relationship to rehabilitation outcomes (Cook, 1978; Cook & Brookings, 1980). Cook (1978, p.12) stated the following regarding the relationship of vocational evaluation recommendations to rehabilitation outcomes:

"While there was a positive and significant relationship between completion of a center vocational training program and subsequent employment, completion of training was made independent of recommendations made in evaluation. . . . In this particular setting, it probably would have been just as effective, and much more efficient, to

have assigned clients to different service modalities by drawing recommendations out of a hat."

Because of the shortcomings of traditional psychometric assessment and work samples for rehabilitation, alternative methods of assessment are being explored. Functional assessment procedures in rehabilitation were formalized in an edited volume based on a 1983 meeting of the National Association of Rehabilitation Research and Training Centers on this specific subject (Halpern & Fuhrer, 1984).

Functional assessment is characterized by several features:

- It includes multiple and different types of instruments (including, if appropriate, work samples).

- It addresses the unique work, education, and community adjustment strengths, needs, and preferences of the individual.

- It should appraise the characteristics of employment, education, and community settings in which the individual could be placed.

- It allows for the ongoing assessment of consumer growth and skill acquisition.

The close relationship of assessment to intervention also is emphasized. Specifically, assessment and related interventions should sample from similar content bases to ensure the direct relevance of assessment results to intervention efforts (Kazdin, 1985; Linehan, 1980). The results from a functional assessment are then tied directly to intervention efforts, as well as the subsequent evaluation of the intervention.

However, functional assessment in rehabilitation is in its infancy (Frey, 1984), a situation which is likely to change both as a result of apparent need and recent legislative changes. The transition initiative (Will, 1984), which has become a central part of the legislation governing special education and rehabilitation agencies (Rusch & Phelps, 1987), mandates that

- adolescents receive training in the skills necessary to become successful in our society while in school, and

- that these persons be connected to community agencies (including VR) through a transition planning process



**Figure 1. Conceptual Model of Functional Assessment**

	Type of Assessment Instrument				
	Norm Reference	Informal	Self- Report	Interview	Observation
<b>EMPLOYMENT</b> <i>Individual</i> - Abilities and Interests - Task Performance - General Adjustment - Social Skills - Self-Determination  <i>Setting</i> - Skill Requirements - Possible Accommodations - Available Supports					
<b>EDUCATION</b> <i>Individual</i> - Abilities and Interests - Task Performance - General Adjustment - Social Skills - Self-Determination  <i>Setting</i> - Skill Requirements - Possible Accommodations - Available Supports					
<b>COMMUNITY</b> <i>Individual</i> - Abilities and Interests - Task Performance - General Adjustment - Social Skills - Self-Determination  <i>Setting</i> - Skill Requirements - Possible Accommodations - Available Supports					

cus the functional assessment process as it relates to the VR process.

The section below provides a conceptual model around which to organize such procedures.

## Conceptual Model

Figure 1 presents a conceptual model of functional assessment, which includes three possible outcome domains for the rehabilitation process and multiple methods of assessment. Additionally, the model emphasizes the interaction between the characteristics of the individual and those of the settings in which he or she could be placed.

*Parameters of the model.* Three broad outcome domains—employment, education, and community adjustment—are identified, for several reasons. First, the new Rehabilitation Amendments and the Individuals with Disabilities Education Act emphasize education, work, and community goals for people with disabilities. Second, recent studies (Halpern, 1985; Halpern, 1993) demonstrate that these three outcome domains are reasonably independent of one another, suggesting that it is not possible to focus on only one area (e.g., providing only vocational services to an individual) and affect positive change in the other two. Third, the available research on the community adjustment of people with disabilities indicates that, in general, persons with disabilities tend to experience varying levels of success in these outcome areas (Wagner & Shaver, 1989).

It is possible to assess these areas through

- norm-referenced measures (e.g., *Test of Interpersonal Competence in Employment*, Bullis & Foss, 1986);
- informal third party rating scales (e.g., *Scale of Job-Related Social Skill Performance*, Bullis et al., 1993);
- self-reports (e.g., vocational interest inventories) and interviews (e.g., *Test of Job-related Social Skill Knowledge*, Bullis et al., 1993); and
- behavioral observations of consumer's placed in employment, education, or community settings (e.g.,

that is to begin by age 16 or 14 if the individual is likely to not finish his or her public education (P.L. 94-142, 1992).

As many adolescents with special needs will have minimal work experiences, ill-defined goals and aspirations, and less than developed work, education, and community living skills, traditional assessment procedures—which provide a static view of the individual—in many cases are not appropriate for this population (Sitlington et al., 1985).

The new Rehabilitation Act Amendments (P.L. 102-569, 1992) redefine the rehabilitation process, and assessment in particular. For instance, the amendments:

- alter the standards for determining eligibility by relying on a "presumption of employability" for all persons regardless of severity of disability;
- emphasize using existing data and information for making eligibility decision and making rehabilitation plans;
- call for a comprehensive examination of the individual's strengths and preferences; and
- mandate the active involvement of the consumer in the assessment process.

Given these two parallel legal and service delivery developments, it is clear that there is a great need to refo-



situational assessments, Hursh & Kerns, 1988).

*Characteristics of the individual.* In order to base the rehabilitation planning process in a context relevant for the consumer, it is essential to first assess the individual's basic cognitive (sensory perceptual capabilities, motor functioning, language skills, spatial-relations, problem solving) and physical (presence of complicating physical condition) capabilities, as these characteristics will, to some degree, influence planning decisions. Particularly with older consumers who may be entering the rehabilitation system some years after leaving school, the absence of assessment data and "hidden" disabilities (e.g., learning disabilities) emerges as a crucial subject to be addressed (Dowdy et al., 1992). Consideration of the individual's different strengths and needs across settings is important to note, as many people perform in different ways across different settings and may exhibit different learning styles or ways to process information (Deshler & Schumaker, 1986). It also is crucial to examine the individual's vocational and life interests and preferences, as there is research to suggest that people are more likely to be happy and successful if their lives correspond closely to their interests and preferences (Loftquist & Dawis, 1969; Nosek & Fuhrer, 1992; Nosek, Fuhrer, & Howland, 1992; Szymanski, Turner, & Her-shenson, 1992).

For a person to maintain and progress in employment, education, and the community, it is mandatory that he/she be able to perform the required tasks of the setting in a satisfactory manner. General adjustment skills refer to the formal and informal skills required to succeed in a particular setting. These skills are associated peripherally with task performance and include dressing and grooming appropriately for the setting, exhibiting enthusiasm and motivation, following safety regulations, being punctual, and so on. Numerous studies provide evidence that the primary correlate of success or lack of success in education, job

placements, and community settings relates to social skills, or the ability to "get along" with supervisors or people of authority (e.g., work supervisors, police, landlord), coworkers and peers on the job or in community settings (Bullis & Foss, 1986; Bullis et al., 1993; Cartledge, 1989; Chetkovich, Toms-Baker, & Schlichtmann, 1989; Foss, Walker, Todis, Lyman, & Smith 1986; Walker & Calkins, 1986).

***The concept of self-determination, or the ability to plan and direct one's own direction and life course in different settings, has assumed major importance in rehabilitation.***

The concept of *self-determination*, or the ability to plan and direct one's own direction and life course in different settings, has assumed major importance in rehabilitation. This ability may be the *most* important aspect of mental health and functioning (Bandura, 1982, 1986) and it is a key element of rehabilitation success (Halpern, 1993; Nosek & Fuhrer, 1992; Nosek, Fuhrer, & Howland, 1992). Self-determination is at the heart of the new Rehabilitation Amendments and is a bold pronouncement of the central role of people with disabilities as equal partners in the rehabilitation process.

*Characteristics of settings.* Modern social learning theory (Bandura, 1982, 1986; McFall, 1982, 1986) and rehabilitation thought (Szymanski, Dunn, & Parker, 1989) suggest that there is an important and critical interaction between the individual and the target setting in which he or she is placed. It is clear that attention must be paid to the skill requirements of the employment, education, and community settings in which the consumer may function, possible accommodations that may be made to address the needs of the individual, and supports which may exist

to foster success for the individual (e.g., coworkers to enlist to help the client) (Gaylord-Ross, Siegel, Park, Sacks, & Goetz, 1990; Nisbet, 1992; Szymanski et al., 1989). Often times, it is attention to these setting variables that spell the difference between placement success and failure (Nisbett, 1992).

## **Project FASTER**

In the section above we have presented the case for using functional assessment procedures and a way in which these procedures can be conceptualized. In the section following, we offer an overview of a project designed to provide such services.

Project FASTER (Bullis, 1993) began in the fall of 1993 with startup funds from an RSA grant awarded to the Teaching Research Division of Western Oregon State College (TR) to develop and provide functional assessment service capabilities at the Education Evaluation Center (EEC), an assessment center administered by TR.

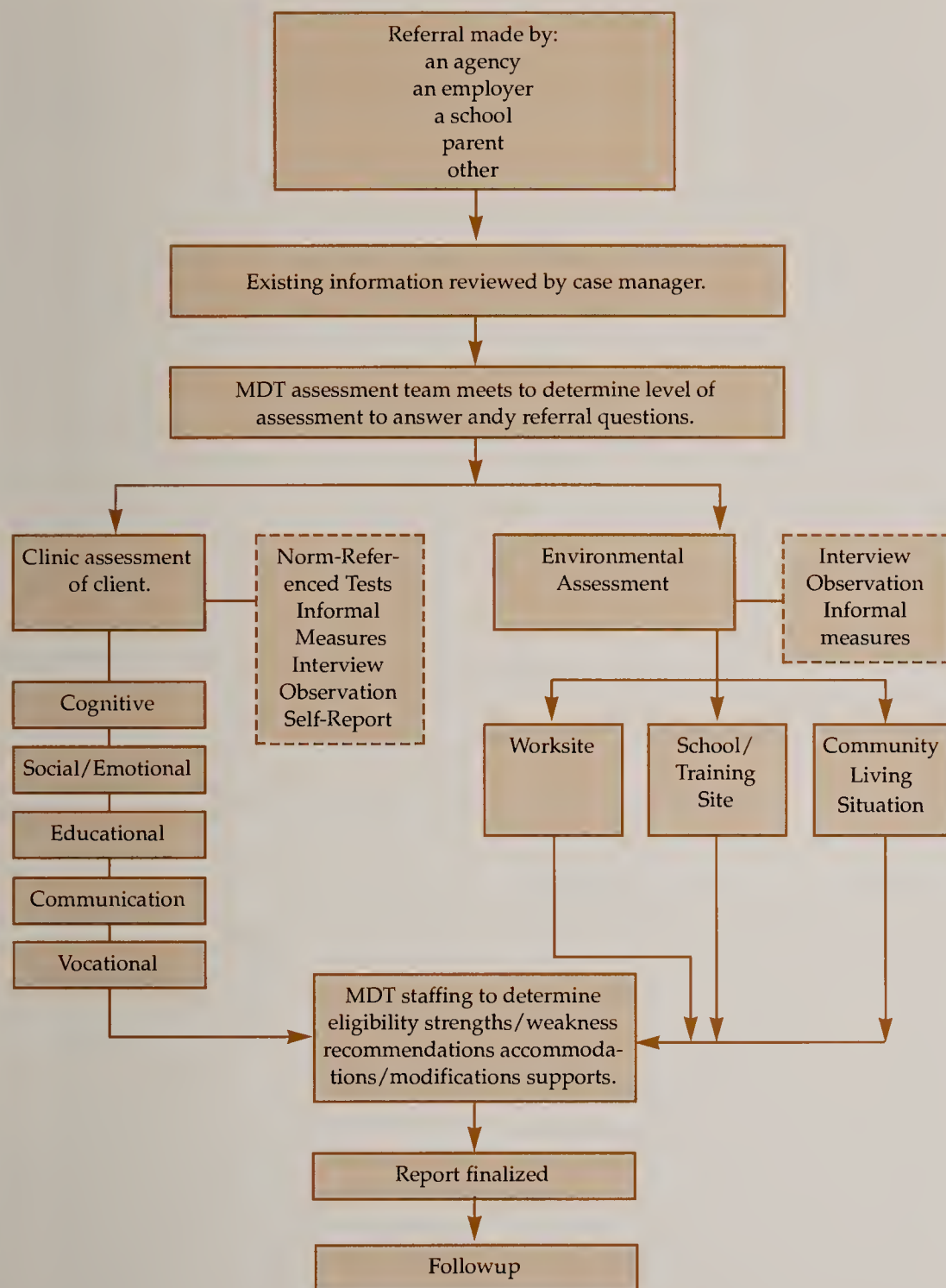
## **Setting and Project Structure**

Both TR and the EEC are located on the campus of Western Oregon State College in Monmouth, Oregon, situated 12 miles west of the state capitol of Salem, 70 miles south of Portland, and 65 miles north of Eugene in the Willamette River Valley, an area in which 80 percent of the state's population resides. The college has a total enrollment of almost 4,000, graduates the largest number of special education teachers in the state, and offers master's degrees in special education and rehabilitation counseling, as well as a number of other disciplines.

TR is a research and development agency funded through state and federal monies and specializing in service provision to persons with special needs. EEC has been funded for over 30 years through state and federal funds through the Oregon Department of Education to offer assessment services to school districts. Over the past 5 years, EEC has received a steady, but small, number ( $n = 4$  to 7) of referrals from re-



**Figure 2. Functional Assessment Model**



habilitation counselors and other adult service providers.

EEC is staffed by a full-time director—who is a school psychologist—a part-time speech pathologist, and a second part-time school psychologist. A Ph.D. level staff person is employed on a contractual basis to assess adults with learning disabilities. Through grant funds, a half-time assessment specialist with a specialty in the transition and rehabilitation of adolescents and adults and a vocational assessment

specialist with extensive experience in job and community placements for persons with disabilities have been hired expressly to work with persons referred to Project *FASTER*.

### **Purpose and Focal Population(s)**

The purpose of the project is to provide functional assessment services for adolescents and adults with cognitive disabilities. Over the course of the 3-

year project, we will increase the number of referrals from a target of 10 in the first year, 25 in the second year, and 25 in the final year.

Ultimately, we hope to develop strong referral sources which will allow these services to continue after federal funding ceases on a fee-for-service basis.

To ground the project in the needs of local service delivery agencies, we have sought close coordination with Oregon's Division of VR, the Youth Transition Project (YTP), a cooperative statewide project administered jointly by VR, the Oregon Department of Education, the University of Oregon (Benz, Lindstrom, & Johnson, 1994), and representatives from disabled student services in Oregon's Community College and Higher Education systems. Upon receiving notification of the grant award, we engaged in intensive conversations with representatives of these agencies. It became clear that, to address their most pressing needs and in recognition of the limited resources of the project, it would be important to identify a primary or focal population to serve.

In line with these discussions, we made the decision to focus project services to adolescents and adults who are learning disabled, suspected of having a learning disability or brain injury, and/or experiencing emotional or behavioral problems concomitant with a learning problem. This population represents the largest disability group within special education and is the fastest growing disability group served through the state-federal VR system (Berkeley Planning Associates, 1989; Dowdy et al., 1993; White, 1992).

### **Philosophy**

Several initial meetings were held with project staff to discuss the project and its basic structure and to review much of the literature presented in the previous section. Drawing from this literature base, the conceptual model (Figure 1), and pragmatic issues surrounding service delivery, we established a general model to guide service and a project philosophy. Figure 2 presents a model of the process and



the way in which services are offered through the project.

In line with our beliefs about functional assessment services, the unique characteristics of the learning disabled population, and the new legal requirements for special education and rehabilitation, we developed the following project philosophy statement.

"We believe that assessment should be an integral part of the rehabilitation endeavor and that it must be grounded in the unique characteristics and needs of the individual. Further, it is essential that assessment be geared to address questions from the rehabilitation counselor or referring agent concerning the individual's unique strengths and weaknesses for functioning within work, family, and community environments. Use of existing information and full input from the client at each stage of the assessment is critical. It is important to gather data on and to assist establishing their perspectives and opinions on pragmatic placement, support, and accommodation issues within these settings.

"Functional assessments offered through the project are conducted by a multidisciplinary team consisting of a psychologist, a speech pathologist, a handicapped learner specialist, and a situational assessment specialist. The assessments include IQ and other traditional psychometric measures, social histories, integration of already completed assessment data, behavioral observation, interview and self-report procedures, and appraisal of the demands, supports, and accommodations of the environments in which the individual may be placed. Client interests and motivation related to training and eventual placements also are identified. An in-depth report from the team includes (a) background and social history; (b) analysis and integration of previous testing; (c) results from functional assessment; (d) results from psychological assessment; and (e) specific recommendations related to training, job placement, work adjustment, environmental accommodations and adaptations, and resources or support services that may be available to the individ-

ual to foster rehabilitation success and community adjustment.

"Following assessment, the referring agent will be able to apply these results and recommendations in a pragmatic and effective program for the client. If needed, continued onsite assessment and followup by a staff person can be provided to assure that the assessment is as beneficial as possible for the transition or rehabilitation professional and the client."

## Developmental Activities

A number of initial developmental activities have been completed and are now being implemented.

*Referral sources and linkages.* In order to solicit initial referrals, we contacted three groups of service providers:

- VR counselors,
- school and rehabilitation personnel involved in the YTP, and
- coordinators of services for students with disabilities in community colleges and institutions of higher education.

Contacts have included mailings (consisting of materials on the project, fee schedule, and referral forms), phone contacts, and—in a few instances—visits with program staff. Additionally, to expand this base of contacts and to focus our initial efforts, we have established and held meetings with an advisory board that consists of transition, education, and rehabilitation service providers, parents of persons with learning disorders, and persons with learning disorders.

We started the project with a bias that one of the reasons that assessments are often judged as "disconnected" to the rehabilitation process is that the referring agent and the assessment specialist do not interact effectively. As a result, there is confusion over what to ask for in the assessment and, conversely, what to provide for assessment results. Stated differently, if assessment results are to be integrated into rehabilitation practice, they must be grounded in the needs of the referring agent who will in turn apply these results to service provision. Thus, we developed a referral packet including a checklist to be completed by

the referring agent to summarize the consumer's background and existing assessment results, release forms necessary to share the results with project staff, and a referral form specifying specific areas of concern which are checked to focus the assessment process.

*Instrument identification.* The EEC already possessed a number of assessment tools for different populations, and at least some of these tools have relevance to the rehabilitation process and fit within a functional assessment approach (e.g., *Woodcock-Johnson Battery*). However, to expand the project's functional assessment capabilities, it became necessary to secure and access other, relevant instruments, which have been identified through an extensive computerized and hand search. The parameters of the computerized search included any books, articles, or instruments written or developed in the past 10 years. Within this timeframe, any material addressing functional assessment, vocational services, learning disabilities, or situational testing was reviewed through the computerized databases of *ERIC*, *Psychological Abstracts*, and the *Educational Testing Service*. A lengthy hand search also was conducted of texts, publications, catalogues, and assessment instruments recommended by colleagues and the advisory board.

Instruments judged as promising (i.e., relevant to the rehabilitation process, possessing acceptable psychometric properties, and addressing a population with learning disabilities or that would be applicable to this population) were catalogued according to age group (adolescent and/or adult) and skills the instrument addresses (e.g., job-related social skills, work production skills, money management). Review copies of the instruments were secured and examined and, if recommended through staff review, were secured and included in the instrument pool for the functional assessments. We should note that few instruments were located to assess the setting requirements of the outcome areas. Given this, we have taken steps to develop measures for this purpose.

**Figure 3. Examples of items from the E-JAM  
Demands of the job**

Physical Demands of the job					Accommodations/ Modifications					Supports— People
1. sit (% of job time)	25% or less	50%	75%	100%	NA	low probability	2	3	high probability	comments
2. stand (% of job time)	25% or less	50%	75%	100%	NA	low probability	2	3	high probability	
3. walk (% of job time)	25% or less	50%	75%	100%	NA	low probability	2	3	high probability	
4. strength	sedentary	light	medium	heavy	NA	low probability	2	3	high probability	
5. eye-hand coordination/ manual dexterity	not critical	mildly critical	somewhat critical	critical	NA	low probability	2	3	high probability	
6. vision	not critical	mildly critical	somewhat critical	critical	NA	low probability	2	3	high probability	
7. hearing	not critical	mildly critical	somewhat critical	critical	NA	low probability	2	3	high probability	
8. work hours	1-2 hrs	3-4 hrs	5-6 hrs	7-8 hrs	NA	low probability	2	3	high probability	
comments										

*Development of environmental assessment measures.* Human behavior and performance are influenced strongly by setting variables (e.g., What are the demands of the setting? What are the aspects of the setting that could be modified or changed?). It then is essential to conduct analyses of the prospective settings in which the individual consumer will, or could, be placed. Unfortunately, as noted above, we were unable to locate instruments to assess the setting demands that supplied information relevant to a rehabilitation perspective. This absence of measures, coupled with the fact that the first referrals we received related to questions about work and postsecondary education placements, led us to develop two measures: the *Environmental Job Assessment Measure* (E-JAM) (Waintrup, Kelley, & Bullis, 1994a) and the *Environmental School Assessment Measure* (E-SAM) (Waintrup, Kelley, & Bullis, 1994b). At this point, we have not developed an environmental assessment measure focused to community living settings because of time

constraints. It is entirely possible that such an instrument will be developed in the future.

Our initial thought was that either the E-JAM or E-SAM should be completed as a routine part of the assessment process, and that—in some instances—completion of these measures should be the responsibility of the consumer in conjunction with project staff. We reasoned that such an activity could assist the individual in gathering information about his or her work or school placements, thereby guiding decisions about his/her own rehabilitation plan.

Both measures have been field-tested at 5 to 10 sites. These efforts have resulted in wording changes and item elimination and combination. Preliminary inter-judge reliabilities have been established for both measures that suggest a reasonable agreement between judges (ranging from .40 to .88 for different sections) and provide a foundation for further psychometric analyses. As the project progresses, we will continue to refine and study these instru-

ments. Both measures have been used in several functional assessments conducted under Project FASTER's aegis.

Figure 3 presents examples of items from the E-JAM. The E-JAM consists of three rating areas for each of five environmental clusters. The three rating areas are *demands of the job*, *accommodations/modifications*, and *available supports*. The five clusters describing the demands of the workplace are based on the skills and characteristics of successful workers for the 21st century identified in the SCANS (*Secretary Commission on Achieving Necessary Skills*) report (1989).

These clusters are:

- *physical demands of the job*,
- *working conditions on the job*,
- *educational demands of the job*,
- *general work behavior*, and
- *social interaction*.

The first rating area focuses on the appraisal of the skill demands of the job and utilizes a 4-point Likert Scale. The anchors (i.e., 1, 2, 3, 4) of this scale for each item have been written to be



Figure 4. Examples of items from the E-SAM

Educational Requirements					Accommodations/Modifications					Supports—People
1. concentration	not critical	mildly critical	somewhat critical	very critical	NA	low probability	2	3	high probability	comments
2. work pace	slow	2	3	fast	NA	low probability	2	3	high probability	
3. organization	repetitive	2	3	varied	NA	low probability	2	3	high probability	
4. work independently	requires supervision	2	3	independent	NA	low probability	2	3	high probability	
5. follow directions	not critical	mildly critical	somewhat critical	very critical	NA	low probability	2	3	high probability	
6. self-monitor errors	low			high	NA	low probability	2	3	high probability	
7. reading	functional	basic	advanced	abstract	NA	low probability	2	3	high probability	
8. writing	functional	basic	advanced	abstract	NA	low probability	2	3	high probability	
9. math	functional	basic	advanced	abstract	NA	low probability	2	3	high probability	
10. visual memory	functional	basic	advanced	abstract	NA	low probability	2	3	high probability	
11. auditory memory	functional	basic	advanced	abstract	NA	low probability	2	3	high probability	
12. comprehension	functional	basic	advanced	abstract	NA	low probability	2	3	high probability	
13. expression	functional	basic	advanced	abstract	NA	low probability	2	3	high probability	
14. spatial orientation	not critical	mildly critical	somewhat critical	very critical	NA	low probability	2	3	high probability	
15. problem solving	not critical	mildly critical	somewhat critical	very critical	NA	low probability	2	3	high probability	
16. computer skills	not critical	mildly critical	somewhat critical	very critical	NA	low probability	2	3	high probability	
17. program entry requirements	high school GED	tech or apparent	community college	college or more	NA	low probability	2	3	high probability	
18. program requirements	credits less 60	60-89	90	90+	NA	low probability	2	3	high probability	
19. task completion/follow through	not critical	mildly critical	somewhat critical	very critical	NA	low probability	2	3	high probability	
20. ask for assistance	not critical	mildly critical	somewhat critical	very critical	NA	low probability	2	3	high probability	
21. accept feedback	not critical	mildly critical	somewhat critical	very critical	NA	low probability	2	3	high probability	
22. time management	not critical	mildly critical	somewhat critical	very critical	NA	low probability	2	3	high probability	
comments										

consistent with the item stem. For example: the item stem "vision" uses "not critical," "mildly critical," "somewhat critical," and "critical" as its rating anchors, and "percent of job time spent sitting" uses "25 percent or less," "50 percent," "75 percent," and "100 percent." The second area, *Accommodations/Modifications*, is presented clearly in the 1990 Americans with Disabilities Act and the Rehabilitation Amendments of 1992, which affirm the individual's right to work (Senate Report 102-357, p. 14-15). In some cases, reasonable accommodations or modifications will have to be made on

the jobsite for the individual to be successful. It, too, is assessed on a 4-point Likert scale. The third area, *Available Supports*, "... is defined as a broad term meant to include having a supervisor, coworker, or other employer/employee provide supervision and support at the worksite..." (Senate Report 102-357, p. 28). Natural supports are part of the ongoing support services mentioned in the amendments and are central to placement success (Nisbett, 1992). These supports are summarized in narrative form in each of the five clusters composing the E-JAM.

Figure 4 presents examples of items from the E-SAM, which is set up in much the same way as the E-JAM. It contains three rating areas in each of four environmental clusters. The three rating areas are *school environment demands*, *accommodations/modifications*, and *available supports*. As for the E-JAM, the first two areas utilize a 4-point Likert scale and the third summarizes information in narrative form. The four clusters are:

- *environmental demands*,
- *general socio-educational expectations*,
- *educational requirements*, and
- *instructional style/evaluation/materials*.

These clusters were identified and written with:

- *recognition of the characteristic strengths and weaknesses of the focal population* (i.e., persons with LD) and
- *through input provided by counselors of students with disabilities in community college and college settings.*

*Data collection.* A projectwide data collection system has been developed to describe:

- the characteristics of the clients served,
- the instruments used in the functional assessments and their results,
- the perceptions of the client and the referring agent regarding the quality of the assessment and their satisfaction with it, and
- the effect of the assessment on rehabilitation success. Satisfaction data are gathered directly from clients and referring agents through a structured interview that is administered by a staff person in a telephone conversation. To examine the possible effect of the functional assessment on rehabilitation success, we will track each client at 6-month intervals by telephone to document work, postsecondary education, and personal experiences. These data will be compared to baseline statistics maintained by Oregon's state VR office (e.g., percentage of clients deemed eligible, months required to enter services from referral) and through a data base maintained by the Oregon Department of Labor (e.g., employment and wage statistics).

## Case Study

At this time (September of 1994), we have been accepting referrals for 9 months, during which we received 31 referrals and have conducted 24 functional assessments under the aegis of the project; these figures are well beyond the goals for the first year. A case study of one of the individuals we have seen is presented below to highlight the functional assessment process.

*Presenting problem.* "Bob" is a 55-year-old man referred for an evaluation by the physical plant supervisor of a large company because he has exhib-

ited obvious reading and writing difficulties. These problems have made it difficult for him to pass the state written *Pesticide Test*, which is needed in order to apply chemicals as part of his position as groundskeeper. Bob currently is supervised by others in these specific activities. At referral, there was a possibility that he might lose his promotion, or possibly his job, if he could not pass the *Pesticide Test*. The company wanted to know if he had a learning disability and if there was a program that could help him improve his reading skills.

*Overview of assessment procedures.* To answer the referral questions, the diagnostic process included:

- an in-depth interview with Bob and his supervisors,
- formal and informal testing (e.g., ability, achievement language, hearing), and
- an onsite visitation and environmental assessment to identify the requirements of the job related to pesticide spraying and reading/writing.

Bob indicated that he had always had difficulty with reading and writing in school and had dropped out in the 10th grade. He has held his current job for 11 years, where he operates machinery and sprays plants by hand. He is a loyal worker and has a supportive wife and family.

To determine his current ability level, the *Wechsler Adult Intelligence Scale-Revised* was administered. The results showed an 18 point discrepancy between the verbal and performance scores, with verbal ability in the below average range and performance well within the average range. This discrepancy indicated relative strengths in spatial organization and visual integration ability. Further language and hearing testing revealed weaknesses in auditory memory and a slight to moderate hearing loss in the lower frequencies in both ears, making word discrimination difficult.

Bob's academic levels were assessed on the *Woodcock-Johnson Psycho Educational Battery* and informal measures, such as the *Burns and Roe Informal Reading Inventory* and *Brigance Informal In-*

*ventory of Essential Skills*. Bob's independent reading level ("reads easily") was at fourth grade with instructional (teaching level) being at the fifth grade level. He was well under the 100 percent accuracy level for reading warning, information, traffic, and safety signs and basic math vocabulary words. While he has difficulty with spelling, punctuation, and capitalization and tends to avoid writing, he is able to make fairly well constructed sentences. Math ability on the *Woodcock-Johnson* was within the average range and he demonstrated skill with basic math operations, including adding and subtracting fractions. His functional problem solving skills exceeded his calculation skills.

An onsite examination of the specific job requirements and completion of the E-JAM revealed that pesticide application was 10 percent of the groundskeeper job. Specifically, Bob needed to be able to properly mix chemicals safely. He also needed to accurately apply them and report their usage. Further, the exact words and math needed to complete the jobs were identified and the reading materials for the job were secured.

Bob was found to have a learning disability in the area of language. Relative weaknesses included difficulty reading technical information, written language, auditory short-term memory, and vocabulary. His relative strengths were his interpersonal skills, math (especially problem solving skills), mechanical skills, and being a reliable worker.

*Recommendations.* At the conclusion of the assessment, Bob's case manager (the staff person coordinating the assessment) visited with him and his wife to explain the test results and talk about possible recommendations. Initially, Bob was in denial regarding his learning disability and did not want anyone coming to the worksite where his coworkers could see that he was getting assistance. Time was taken to talk about what a learning disability is and to note some well-known persons who are learning disabled. Suggestions for adaptations and accommodations that



could be made in the worksite were given. With support from project staff and his wife, Bob helped decide on the following recommendations:

- Obtain labels and directions of pesticides used in his job in pictorial form from the companies that make the chemicals.

- Seek services from VR for assistance in obtaining a job trainer who would work with Bob to teach him the reading and writing skills he needs in order to perform the pesticide applications portion of his job. It was also suggested that the trainer could work with Bob to prepare him to take the state examination.

- It was suggested that, until the aforementioned recommendations could be implemented, Bob should approach his supervisor about being assigned primarily to grounds work and machine operation.

- If Bob can get a copy of the actual pesticide labels (either the original or simplified ones), his wife offered to do additional work with him at home.

- It was suggested that Bob's program be reviewed 8 months after adaptations have been initiated.


- Based on Bob's past report and hearing test results, it was recommended that he see an audiologist to discuss his hearing loss.

*Outcome.* Project staff met with Bob's supervisors to explain his disability. The suggested adaptations and accommodations were discussed. The involvement of a trainer to teach Bob the needed skills was viewed positively by the supervisors.

Referral was made to VR by project staff. Initial contact by the vocational specialist with VR indicated that Bob should be eligible for services and that the assessment reports would be very helpful in conceptualizing training and support services. Plans now are underway with VR to secure a job coach to assist in the training. The job coach will work with Bob outside of the work environment for the last hour of the work day and for another hour after work in order to train him in the specific areas noted above. Project staff will

continue to monitor his progress to insure that success is achieved.

## Conclusion

Project *FASTER* represents one of the first attempts to provide functional assessment services within a rehabilitation context for persons with learning disabilities. We are pleased with its beginning and optimistic about its future success and place in the service delivery system. Functional assessment presents the rehabilitation field with a pragmatic approach to the appraisal of clients and the planning of interventions. However, many of these procedures and needed instruments have not been developed and/or field-tested. Thus, it is clear that extensive work is necessary to refine and improve this process. Given the close relationship between functional assessment and interventions, these efforts will affect not only assessment but, ultimately, the type and effectiveness of the services provided, resulting in greater success for individuals with disabilities. 

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# Project CIRCLE:

## *Strategies for Increasing the Choice, Control, and Competence of Survivors of Brain Injuries in the Vocational Rehabilitation Process*

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**R**eturn to meaningful paid employment has proven to be exceedingly difficult for most persons recovering from brain injuries; the great majority remain unemployed. Moreover, those survivors fortunate enough to secure competitive jobs usually find themselves working in positions with much less prestige, responsibility, and compensation than they had in their pre-injury employment situations. Thus, many survivors find

themselves living in poverty and, due to the negative reactions of others to their changed conditions and circumstances, often isolated from the circle of family, friends, and coworkers which had comprised the core of their lives in the community.

Project CIRCLE (Capitalizing on Residual Capacities in order that Life is Enhanced) was established to demonstrate a consumer-driven, community-oriented, and employer-responsive approach to satisfying the desire and need of persons surviving brain injuries for a return to the world of competitive work in positions as commensurate as possible with those they held prior to their injuries. The realization of such opportunity is viewed by many sur-

vivors, members of their families, and leading supported employment practitioners as essential for the successful re-integration of survivors into the community from which they have so long been removed while undergoing the initial intensive stages of recovery from their injuries. The strategic emphasis upon identification, assessment, development, and use of residual capacities has been adopted from some of the best practices in the fields of cognitive and vocational rehabilitation. The project title is an acronym for this emphasis and the focus on quality-of-life outcomes. It is also synonymous with one of the major project strategies, namely, development and use of "circles of support" in the design and implementation of personal career and lifeplans with survivors.

Project CIRCLE is operated by ICON Employment Services and is funded through a 3-year grant from the Rehabilitation Services Administration. ICON is a private, not-for-profit corporation, based in Alexandria, Virginia, founded in 1985 through the combined efforts of five Northern Virginia Community Services Boards and the Specialized Training Program at the University of Oregon for "supporting individuals with severe disabilities in integrated work settings." ICON provides supported employment services directly to Northern Virginia residents, as well as training and technical assistance to other purveyors of such services. The agency developed its initial reputation from the provision of quality services to individuals with severe developmental disabilities, but it has used its success and increasing capacities to serve an increasing number of people with other types of severe disabilities.

**Vocational rehabilitation (VR) for persons surviving traumatic or acquired brain injuries, especially in the form of supported employment, is relatively new to the insurance companies, state VR agencies, and private rehabilitation organizations that fund and deliver services to these consumers. Advances in medical technology and therapeutic intervention and the resultant increase in rates of survival and community re-entry among these people over the past decade have been the primary reasons for their increased demand of VR services. The growing demand of survivors for supported employment services in particular springs in large measure from their desire to return to the world of work which they inhabited prior to their injury, rather than the sheltered work settings so often prescribed for them due to their need for more structure and support in their lives.**



Project CIRCLE consumer goals, strategies, and participants are summarized in the next section. This overview is followed by stories about two persons, as told by their employment specialists, which illustrate the nature of and results from our work with individual survivors. A final section summarizes the lessons we have learned in this regard over the first 19 months of the project and how we hope to improve service operations over the remainder of the demonstration grant period.

## Consumer Goals, Strategies, and Participants

The focus of this article is upon the consumer-oriented goals of Project CIRCLE, which are to:

- increase the survivor's knowledge of his/her vocational capabilities and potential, especially with respect to those residual capacities which are transferable to post-injury employment situations;
- expand knowledge of the survivor's development options and aspirations and related interests and preferences with respect to job types and work settings; and
- boost the survivor's ability to choose from among these various options, decide upon a career path, and embark upon that path by securing a job situation which reflects these choices and decisions and is as commensurate as possible with his/her pre-injury job situation.

The other major project goals have to do with increasing staff and employer knowledge and capabilities with respect to supporting and employing survivors of brain injuries and enhancing the capacity of the state and local VR systems for delivery of supported employment services to survivors.

The principal project strategies for achieving its consumer-focused goals include:

- a personalized career and life planning process, which empowers the survivor to make informed choices and decisions about his/her future and provides a flexible blueprint for pursuing his/her chosen career path and lifestyle;

- the circle of support, comprised of the individual and significant others in his/her life, including family members, rehabilitation staff, and/or employer representatives, who assist and support the consumer in developing and implementing his/her career and lifeplan;

- the pre-injury profile, developed by the consumer and his/her circle of support, with facilitation by the employment specialist, to identify residual capacities and needed compensatory strategies and to help the individual to choose what career and job-related options to explore;

- volunteer and unpaid work experience, developed and used to assist the consumer in exploring career and job-related options, making decisions and choices in this regard, and developing the residual capacities, compensatory strategies, and additional skills needed to enact them;

- individualized supported employment services, designed to assist and support the consumer in securing and sustaining paid work in positions matched to his or her evolving career choices, job interests, workplace preferences, residual capacities and compensatory strategies, and presence and participation in the life of the community; and

- the post-injury profile, developed on an ongoing basis by the consumer and his/her circle of support to reflect and record the survivor's changing and/or refined career, job, and lifestyle choices and everincreasing knowledge and skills, especially in regard to use and development of residual capacities and compensatory strategies.

These strategies have been implemented to varying degrees with the 16 people entering Project CIRCLE between December 1992 and April 1994 from among the 19 accepted for services Table 1 provides summary demographic information on these people and Table 2 provides summary descriptive information on the nature of their injuries and the residual capacities and existing deficits which they presented to staff upon entering the project.

## Eleanor's Story<sup>1</sup>

"Eleanor" was referred to Project CIRCLE at the age of 20, 3 years after surviving a traumatic brain injury (TBI) incurred during an alcohol-related automobile accident while she was a junior in high school. At the time of referral, she had been living for a year at Learning Services (LS), a private residential treatment facility located just a few miles from her mother and her home in suburban Northern Virginia. There she received multiple therapies, performed volunteer clerical work, and earned her GED, with the cost of services covered by insurance. LS staff were in the process of developing her discharge plan, with part of the process involving a referral to the Virginia Department of Rehabilitative Services (DRS), which assigned her a counselor. The DRS counselor had, in turn, referred her to Project CIRCLE, which was just initiating operations.

In December 1992, we began meeting with Eleanor, her mother, her DRS counselor, LS staff, and a case manager from the DRS-funded Head Injury Services Partnership (HISP). These people, who have had eight meetings to date, were, and continue to be, her circle of support. The personal career and lifeplan we have developed and implemented with Eleanor and the other members of her circle (the current status of which is summarized in Table 4) has addressed not only her employment needs, but her needs in many other areas of her life as well. From the start, she has presented a number of residual capacities that have proved invaluable in furthering her rehabilitation, pursuing employment, and re-entering community life. In the words of her mother, they include "a stubborn and strong will, a very sensitive, empathetic, and creative nature," and

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*Ms. Yaffe is Executive Director, Ms. Fitzgerald is a program manager, and Mr. Dunfee and Ms. Wheatley are employment specialists at ICON. Mr. Wurzbacher is an independent consultant and evaluator of Project CIRCLE.*



**Table 1. Summary of basic demographic characteristics of persons accepted into or entering Project CIRCLE from October 1, 1992, through April 30, 1994**

Demographic Characteristics		Number	Percentage
Sex (n=19*)	Male	16	84
	Female	3	16
Race/Ethnicity (n=19*)	Caucasian	17	89
	Hispanic-American	2	11
Years of Formal Education (n=19*)	8-9 years	2	11
	10-13 years (H.S. diploma or G.E.D.)	9	47
	14 years (A.A./L.P.N.)	3	16
	16 years (B.A.)	1	5
	18 years (B.A./post-baccalaureate study)	2	11
	20 years (M.Ed./doctoral study)	2	11
Age Upon Project Entry (n=16**)	20-29 years	5	31
	30-39 years	4	25
	40-49 years	5	31
	Over 50 years	2	13
Occupational Status at Time of Injury (n=16**)	H.S. student (1 part-time semi-skilled)	2	13
	Graduate student (teaching assistant)	1	6
	Semi-skilled	2	13
	Skilled (technical/mechanical—1 unemployed)	5	31
	Management (bar/night club)	1	6
	Professional (nurse/computer analyst/ accountant/ architect/educational consultant)	5	31
Current Marital Status (n=16**)	Single	4	25
	Married***	7	44
	Separated	2	13
	Divorced	3	19
Current Living Situation (n=16**)	Lives with spouse***	7	44
	Lives with parent(s)	5	31
	Lives with other relations	2	13
	Boards at friend's house	1	6
	Lives in own apartment	1	6
Current Public Assistance (n=16**)	Receives SSDI (range: \$612-\$900; median: \$698; mean: \$719)	7	44
	Receives SSI (\$434/month)	1	6
	Receives no public assistance***	7	44
	Not reported	1	6

\* 19 individuals accepted into Project through April 30, 1994

\*\* 16 of 19 persons accepted actually entered Project through April 30, 1994 (others chose not to)

\*\*\* Includes person who died in November 1993

"always, a strong work ethic." She had evidenced and retained the latter from the five part-time jobs she held prior to her injury, including four in retail sales and one as a receptionist/clerical worker. Most importantly, Eleanor clearly knew what she wanted, which in her words was to: "Get up, get ready for work, and go to work from 9 to 5"

and "live a life of my own in a place of my own the way I'm supposed to."

Eleanor initially expressed a desire to become a secretary and—because she needed an inexpensive way to continue her physical rehabilitation in the community—to become involved with swimming. The Fairfax County Park Authority (FCPA) offered her a perfect opportunity to work on both goals at its

center. We arranged volunteer work for her as a front-desk receptionist at the center, where she could re-hone her customer service, telephone, and cashier skills in exchange for free use of FCPA facilities, including a swimming pool. Eleanor had difficulty learning to use the telephone (given her limited use of one arm), make change, give out information (because of her memory prob-

**Table 2: Summary aspects and characteristics of brain injuries survived by Project Circle consumers accepted into or entering project from October 1, 1992, through April 30, 1994**

Aspects and Characteristics of Injuries		Numbers	Percentage
<b>NATURE/CAUSE OF INJURY</b> (n=19*)	<b>Traumatic Brain Injury</b> (closed head)—due to:	10	53
	> Vehicular accident (7)		
	> Rock climbing accident (1)		
	> Fall while intoxicated (2)		
	<b>Traumatic brain injury</b> (open head—gunshot)	1	5
	<b>Acquired brain injury</b> —associated with:	8	42
	> Stroke/cardiovascular incident (5)		
	> Tumor (1)		
	> Temporal lobectomy (1)		
	> Neurosyphilis/lyme disease (1)		
<b>POST-INJURY COMA</b> (n=19*)	Coma of 5-32 days (mean = 14 days)	9	47
	No coma	6	32
	Not reported	4	21
<b>AGE AT TIME OF INJURY</b>	16-19 years	3	16
	20-29 years	5	26
	30-39 years	4	21
	40-49 years	6	32
	50 years	1	5
<b>TIME SINCE INJURY</b> (n=19**) (at time of Project acceptance)	1 year to 1 year, and 11 months	7	37
	2 years to 2 years, and 11 months	4	21
	3 years to 3 years, and 11 months	3	16
	4 years to 4 years, and 11 months	5	26
<b>TIME SINCE ACTIVE SERVICE</b> (at time of Project entry—n=16**)	Receiving active service upon entry	8	50
	Within past 6 months	3	19
	Within 6 months to 1 year	1	6
	Within 1-2 years	3	19
	Over 2 years	1	6
<b>RESIDUAL CAPACITIES</b> (n=16**) (cited for at least 25% of consumer participants at time of Project entry)	Motivation to work/improve capacities	12	75
	Social skills	8	50
	Independence in activities of daily living	8	50
	Supportive family members	7	44
	Word and/or symbol recognition	7	44
	Job-related skills in pre-injury career field	6	38
	Drives car	6	38
	Writing skills	5	31
	Computer skills	4	25
<b>REMAINING DEFICITS</b> (n=16**) (cited for at least 25% of consumer participants at time of Project entry)	Memory	15	94
	Executive functions	14	85
	Mobility/balance (3 use cane and/or wheelchair)	10	63
	Medications	10	63
	Stamina/endurance	10	63
	Visual impairment (1 legally blind)	9	56
	Anger/frustration/impulse control	8	50
	Speech/communications	7	44
	Personal insight/goal orientation	7	44
	Attention/concentration	7	44
	History of substance abuse	6	38
	Seizure activity	5	31
	Gross motor functions	5	31
	Fine motor functions	5	31

\*As reported for 19 persons accepted into Project during this time frame

\*\*As reported for 16 of persons accepted who actually entered Project (others chose not to)





Brian Bushlow, a TBI survivor, prepares dough at Pizza Hut. (Photo by David Galen Photography.)

lems), and getting around the center in her wheelchair (due to architectural barriers); but her initial supervisor, the center director, and other center staff were very supportive of her and the project employment specialist and they were able to work out all these problems together, including finding someone to spot her while she was swimming. The staff even took part in one of Eleanor's circle of support meetings. Unfortunately, a new director was assigned to the center who was not as supportive of the situation; however, by this time she was ready for the next step—her career.

In this regard, FCPA once again came through with an appropriate job opportunity for her as a volunteer clerical assistant at the headquarters of its Recreation Services Department. This position has given her a chance to de-

velop basic filing, copying, and record-keeping skills. However, we encountered a number of problems we had not faced at the recreation center. For one, whereas the center had been an open-space facility, Recreation Services operations were located in a number of offices and Eleanor had to work in several of them over the course of the day. She would often get lost going from one office to another. Further, she had fewer noticeable cues for doing her job (e.g., ring of the phone, patron asking a question), and she was forgetting what she was supposed to do. We tried to instruct her in the use of a *Daytimer* (an appointment book) to write down assignments and instructions; but this was not as effective as reminders from coworkers or project staff, who were not always available for this.

She also had difficulty arranging for a cab to take her to work in the morning, and the attendant/driver hired by her mother to drive Eleanor home was usually late. The late pickups especially concerned her coworkers, as Eleanor had to wait at dusk and behind the building for her ride.

Most of these problems were resolved by Eleanor's circle with the help of Recreation Services staff, who have been most supportive. Eleanor has learned to get around the building on her own and become proficient at several basic clerical tasks that have to be performed on a regular basis. In addition, she has become a member of the department's disability awareness team, which is responsible for training all Recreation Services staff. She has, in fact, become such a valued staff

**Table 3.**  
**Summary of Eleanor's Pre-Project Employment Experience and**  
**Nature of and Results from Delivery of Project Employment Services**

Date Project services initiated	Position at time of injury	Post-injury/ pre-Project work experience	Project career field/initial job choice	Number of job development contacts	Project work experiences	Work schedule/ length of experience
12/15/92	High school student, with previous part- time clerical and retail sales experience in five different positions	Volunteer clerical work at private residential treatment center	Administrative assistant or secretary in human service or animal service office—current goal is to secure paid data entry position anywhere	14 (including 10 employers which did not have type of job or supportive environment wanted and needed)	Front desk receptionist at public recreation center (unpaid work experience)  General clerical worker in government office (volunteer)  Data entry clerk in large private company (unpaid work experience)	4 da/wk, 4 hr/da (4-10/93)  2 da/wk, 4 hr/day (10/93- present)  3 da/wk, 6 hr/day (1/94- present)

**Comments**

Due to memory and visual processing problems resultant from her injury, Eleanor has had ongoing difficulty learning and remembering her work schedule, how to do job tasks, and how to get around the workplace. But she has been adverse to using compensatory strategies which she says make her look "like a dumb ass." She has refused to use a tape recorder, but, after repeated encouragement, has finally begun to write things down making use of "Daytimer" materials. As for getting around the workplace, the ICON employment specialist initially tried maps with color-coding, photographs, and written directions. However, what finally worked was having the employment specialist accompany Eleanor around the building while letting her write down directions, get lost, refind her way, and correct her directions, and then very gradually fading her presence and support.

member that she was recently nominated for the FCPA *Volunteer-of-the-Year Award*, one of just 70 people accorded this honor out of over 4,000 volunteers. This mutual admiration and respect are so great that Eleanor continues to volunteer at Recreation Services 2 days a week, even though she has moved on to her last and most demanding unpaid work experience.

This most recent job, which began in January, is with Electronic Data Systems (EDS), a private firm located in a large office building. In a work circle transition planning meeting involving Eleanor and ICON, EDS, and FCPA personnel, we learned from a Recreation Services staff member that Eleanor was not using her *Daytimer* at work. So we had to place more emphasis on providing reminders and rewards for her to use this compensatory strategy. Once again, learning how to

get around the building proved a major problem for Eleanor, but we finally solved this one. (See Table 3, "Comments.") Then, as we began teaching Eleanor her new job, we discovered that her computer skills were not as advanced as assessment results had led us to believe. As a result, our instruction here has focused on the learning of data entry skills, since the functions to be performed are less complicated than those involved in wordprocessing and her numerical capabilities are pretty strong. Building off EDS use of a work-team approach to operations, we formed a circle of support at the jobsite, which has helped her to develop and make use of a "mini-manual" of instructions and to increase use of her *Daytimer*. Moreover, she has, in congruence with the advice of her supervisor, decided that she wants to become a data entry clerk. So, we have

helped Eleanor to refine her job goal, are developing her job skills accordingly, and have begun to look for a paying job of this type.

As noted earlier, we have also been working with Eleanor on a number of other pursuits in her life, which are summarized according to type and achievement in Table 4. Much of the help and support provided in these areas has come from her mother, who is her closest companion, but who can occasionally be overly protective. In addition, the time, energy, and effort she has expended on Eleanor's behalf have had some adverse effects upon her own job situation, and she has had to face some major financial problems related to Eleanor's living at home. Thus, the circle of support has also served to help Eleanor and her mother work things out when concerns and issues begin to strain their relationship.



**Table 4.**  
**Nature and Extent of Eleanor's Goal Achievement in Life Areas Outside of Employment**

Goal Area	Goal Summary	Progress Toward Goal Achievement
Strength/stamina	Increase strength and stamina in order to be able to work full-time.	<b>Considerable progress:</b> Through volunteer and unpaid work, swimming, PT, and related exercise, Eleanor now works 4-6 hours a day, 5 days a week. However, her swimming time has decreased due to her increased work schedule and transportation problems.
Compensatory strategies	Develop and make use of functional system to compensate for memory and visual processing difficulties.	<b>Some progress:</b> Eleanor has bi-focals, but rarely wears them because they give her headaches. DRS bought her a track ball mouse for computer use at home and work and recently completed home and work accessibility surveys. (Also see Table 5.)
Transportation	Arrange for transportation so as to get where she needs to get on time.	<b>Some progress:</b> Eleanor can arrange for cab and make use of cab vouchers to get to and from work on time. However, she relies primarily on her mother to get her everywhere else.
Financial	Secure Social Security benefits, funds to pay for transportation, physical therapy, and attendant.	<b>Some progress:</b> After long ordeal and with mother's help, Eleanor secured SSI and large back payment. DRS provides unpaid work experience stipend, HISP pays for cab vouchers, DSS pays for some attendant services, and the insurance company paid for some PT at home.
Weight control	No formal goal set.	<b>No progress:</b> Eleanor was going to Weight Watchers, but had to stop due to lack of money.
Education	No formal goal, but wants to take courses related to career goal and avocational interests.	<b>Little progress:</b> The employment specialist is exploring the possibility of having Eleanor audit a course at a local community college. However, barriers to her enrollment and participation include lack of time, transportation, and money.
Community presence and participation	No formal goal set, but wants to get out and do more with people her own age (one reason she wants to drive).	<b>Some progress:</b> Eleanor's primary companion is still her mother. However, Eleanor occasionally participates in recreational activities with survivors' group, serves as a volunteer trainer in a recreation department disability awareness classes, and performs weekly volunteer job in church daycare program. She got the latter job without assistance.

### Andrew's Story<sup>2</sup>

"Andrew" was born in 1943 and grew up in a close-knit family with two parents and two sisters, "Mary" and "Marlena." He was diagnosed as dyslexic in his early primary school years but never received special educa-

tion services (this being prior to the advent of P.L. 94-142). Mary reports that her brother did not do well in school and was regarded as lazy by his teachers and frequently ridiculed by his teachers and his peers. However, he was given social promotions and was graduated with his class. Following

high school, he drifted through a series of jobs until he purchased a gas station, which he ran so well he was voted employer of the year by a local fraternal order. After marriage and his first child, he sold the gas station because he was having difficulty with the required paperwork. He started a lawn mainte-

nance business, which he worked until 1969, when he was drafted into the U.S. Army; he served a tour of duty in Vietnam. Following this experience and the death of his mother shortly after his return home, he began drinking heavily and subsequently divorced his wife. Over the next 10 years, he lived and worked in a number of places, married and divorced two more times, and fathered the last of his five children. He eventually settled in Washington, DC, where, in 1976, he acquired a job as a bartender at a popular night spot in Georgetown. He worked his way up to club manager, a position he held for 10 years and in which he earned a reputation as a hardworking and responsible employee. Toward the end of this period, he returned to heavy drinking, began using illicit drugs, moved in with a woman addicted to cocaine, and spent his inheritance (received following the death of his father) bailing this woman out of jail and paying for her attorneys. According to Andrew, life just prior to his injury consisted of "working, drinking, and sleeping, and not always in that order," such that he had been demoted to bouncer at the club, being kept on only out of the owner's sense of loyalty to a longtime employee.

One day, while at work in the Spring of 1991, Andrew suffered a stroke due to a cerebral hemorrhage, which left him in a coma for 21 days and with severe receptive and expressive aphasia, dementia, and a slight physical disability. After an operation and a 4-month stay in two hospitals, he was transferred to a nursing home, where he lived for over a year while receiving occupational, physical, cognitive, and speech therapy on an outpatient basis at a local hospital. According to Mary, Andrew never really understood what had happened to him or why he was in a nursing home. As it was apparent he wanted out, Mary provided him with the emotional and financial support he needed to leave the nursing home and move into his own apartment in January 1993. One month later, he had his first meeting with the staff from Project CIRCLE, to which he had been referred by his DRS counselor. He was 49 years

old and a year and a half removed from having survived his stroke.

Andrew's circle of support is made up of his sister Mary, with whom he is very close, and the project employment specialist. Andrew had a number of former friends from his club days and he has visited them upon occasion at the club, but none of these relationships has survived his injury. The employment specialist did arrange a meeting with Andrew and his outpatient therapy team, but Mary refused to attend and Andrew—being a private person anyway—proved uninterested in pursuing use of this particular circle. The initial meetings between Andrew and the employment specialist required that Mary be present, as Andrew speaks in short words and phrases which are not easily understood and can have multiple meanings. He also has difficulty processing information, becomes easily confused in conversation, and, thus, tends not to talk much. The communication challenge this presented to the employment specialist was such that he had to rely on Mary as a translator for nearly 3 months before he reached the point where he could converse directly with Andrew. But the employment specialist's really major hurdle was Andrew's severe lack of self-esteem, further complicated by his apparent inability to understand the cause and effects of his injury.

From his very first meeting with the employment specialist, Andrew would constantly berate himself with such comments as "I'm stupid," and worse. In his more depressed moments, he would threaten to commit suicide, although he never actually attempted it. He expressed a desire to return to work, but he was obviously fearful of doing so, for he presented arguments in response to any suggestions made by the employment specialist in this regard and, at times, would become openly hostile when he felt the "return-to-work issue" was being pushed too hard. In response, the employment specialist decided to bypass the matter for a while and work with Andrew on his expressed desire to "learn how to get around town" on his own. With the use

of simple maps drawn by the employment specialist and his provision of a lot of intensive travel training, within 2 months Andrew was able to get around town on his own using public transportation. As Andrew said that he also wanted to meet people, both Mary and the employment specialist encouraged him to participate in survivor and stroke group activities, but Andrew gave up on these endeavors within a very brief period of time, saying that he had tried them only for his sister's sake.

Finally, after several months, the employment specialist renewed efforts to get Andrew to explore various career and job options. Although Andrew agreed that it was not in his best interest to return to the beverage service industry, he did not feel qualified to do anything else and refused even to express interest in other options. Over the next few months, the employment specialist set up a number of job exploration activities in various occupational areas and settings, including some job interviews. Andrew attempted to sabotage them by not being ready for appointments, arguing that he did not want to go, dressing and acting inappropriately, and, upon occasion, refusing to even get out of the car. Still, at those times when the employment specialist was able to get him to cooperate, Andrew showed himself to be attentive to directions, pleasant to work with, and capable of becoming proficient at manual work tasks. Thus, despite his frequent protestations and efforts at sabotage, he was offered two different jobs, but refused them both. In September 1993, the employment specialist was able to get Andrew to try out a couple of volunteer jobs, but he soon lost interest and quit both.

The turning point in this story occurred when Mary's husband was diagnosed as having stage three lung cancer, with the only hope of recovery being a radical and expensive treatment not covered by their health insurance. As a result, Mary and her husband have been spending nearly all their time and money pursuing this treatment, such that Mary has had considerably less time, energy, and resources to expend



**Table 5.**  
**Summary of Andrew's Pre-Project Employment Experience and**  
**Nature of and Results from Delivery of Project Employment Services**

Date Project services initiated	Position at time of injury	Post-injury/ pre-Project work experience	Project career field/initial job choice	Number of job development contacts	Project work experiences	Work schedule/ length of experience
1/15/93	Nightclub employee (1976-91, began as bartender, became manager, but demoted to bouncer just prior to injury)	Clerical volunteer in hospital	Initially not sure—decided on any paying job in order to help out his sister (see comments)— his goal is to secure full-time position with his new employee	19 (including 2 paid job offers, both refused, prior to one he accepted)	Clothes sorting (volunteer)  Recycling (volunteer)  Custodial/ maintenance (\$6.00/hour)	1 da/wk, 2 hr/da (9/93)  1 da/wk, 2 hr/da (9/93)  5 da/wk, 4 hr/da (4/94-present)

**Comments**

For almost a year, Andrew displayed a high degree of anxiety, uncertainty, and insecurity about work outside the beverage industry. This psychological barrier was overcome when his brother-in-law was recently diagnosed with inoperable cancer, for which radical treatment, not covered by insurance, is being sought. Andrew decided he had to work in order to help his sister, who is his closest friend, pay the medical bills

on Andrew. After a month of contemplating this new and potentially devastating situation, Andrew decided it was time for him to get a job so he could provide financial support to his sister. At this juncture, he began to proactively engage the employment specialist in planning and carrying out a job search, which resulted in his securing a part-time custodial and building maintenance position just recently. His most difficult initial task involved learning how to get around the building in accordance with a work schedule, but he was able to do so through the use of "schedule maps" drawn up by the employment specialist and by having Mary teach him how to tell time. Although resisting renewed attempts to engage him in basic literacy instruction with a tutor experienced in teaching adults with learning disabilities, Andrew has begun to memorize the names of people at work and the words he must say to clear security by writing them over and over and over again each night. In addition, he has, with some help from the employment specialist, begun to pay his own bills, maintain his checkbook,

make his own medical appointments, and pick up his medications—all tasks previously carried out by his sister. He also has started seeing a podiatrist for a long-standing, long-untreated foot ailment which has worsened with his job due to the hours he spends on his feet. Even though his foot may require surgery, he wants to have it taken care of as he wants to become a full-time employee; in fact, due to his taking on

extra job duties, his work hours often actually exceed 40 per week. Moreover, Andrew has decided that he wants to begin "working out" and, with help from the employment specialist, has arranged with a local recreation center to perform volunteer work in exchange for use of its exercise facilities. Finally, Andrew no longer speaks of suicide and seldom refers to himself in a self-deprecating manner. He has, after nearly 2 years, returned to the world of work and is becoming a more self-reliant individual who is contributing to the welfare and well-being of his natural family. He has even started to think about long-term goals (not yet included in his career and lifeplan or in Tables 5 and 6), saying he wants to someday reconcile with the children he has abandoned and eventually retire to Maine to live in the home of his great aunt, who died late last year.

**Lessons Learned**

Eleanor, Andrew, and other survivors of traumatic and acquired brain injuries involved in Project CIRCLE have taught

***Eleanor, Andrew, and  
other survivors of  
traumatic and acquired  
brain injuries involved  
in Project CIRCLE have  
taught us much over the  
past 19 months***

**Table 6. Nature and Extent of Andrew's Goal Achievement in Life Areas Outside of Employment**

Goal Area	Goal Summary	Progress Toward Goal Achievement
Transportation	Travel independently on Metro.	<b>Goal achieved:</b> After 2 months of travel training by the ICON employment specialist, Andrew "became quite proficient in getting back and forth from home unassisted." HISP also - provided funds for other types of travel, but had to cut in back this regard due to funding limitations. Andrew learned to travel to and from his new job using public transportation on his own and without any problems.
Education	Learn to read and write.	<b>Little progress:</b> Despite diagnosis of dyslexia during his early school years, Andrew received no special education and was promoted through school without learning basic skills. The employment specialist referred Andrew to a literacy program for a tutor experienced in teaching adults with learning disabilities, but he has not chosen to pursue this option. However, since starting his job, he has begun memorizing names of coworkers and words he needs to clear security by writing them over and over again.
Medical	Take care of foot.	<b>Some progress:</b> Prior to his injury, Andrew had problems with corns and callouses on one foot. The stroke changed the foot fall, resulting in an awkward walk, and caused an extreme hardening of his toenails. Although advised to see a podiatrist over a year ago, Andrew refused to do so, due in part to the expense involved, as a result of which he developed a chronic sore on the foot. The sore becomes extremely painful when Andrew must stay on his feet for extended time periods. His new job requires him to do this, so he has finally started seeing a podiatrist, who regularly cuts and shaves his nails and treats the sore and recently prescribed inserts, all in hopes of correcting his walk, alleviating his foot pain, and giving his foot sore an opportunity to heal. However, foot surgery may be required.
Compensatory strategies	Learn to get around town. Learn to get around the new worksite and clean each area in accordance with time schedule.	<b>Goal achieved:</b> The employment specialist helped Andrew to develop "basic maps" for learning how to make use of Metro and again to help him learn how to get around his place of work. The latter included labeling the building map with the times Andrew had to arrive to clean each area. This also required that his sister teach him how to tell time, making use of a mock clock secured by the employment specialist. Andrew can now get around town and get around his jobsite on schedule without assistance.
Community presence and participation	Go places and meet people	<b>Some progress:</b> Despite stating this goal and receiving suggestions for activities with a survivors' group and a stroke club, Andrew resisted taking action in this regard. Since starting his job, however, he has decided to do volunteer work at a county recreation center in exchange for free use of workout facilities and free tuition for classes. This activity will start once his foot problem has been resolved.
Mental health	No formal goal set, but activities have been suggested.	<b>Some progress:</b> Rehabilitation staff had responded to Andrew's frequent self-deprecating and occasional suicide "jokes" by suggesting he join a stroke club and seek individual therapy, but he refused referral help in this regard. However, since starting his new job, Andrew has not mentioned suicide, and he has greatly reduced the frequency of his self-deprecating comments.



us much over the past 19 months, including the following:

- *Support in securing and retaining competitive employment is important to survivors for reasons that go beyond income.* In this regard, Eleanor and Andrew are typical of the people served by Project CIRCLE. They want to work because they do not want to be poor and dependent upon Social Security. Equally as important, they regard competitive employment as symbolic of recovery and independence, as an indication that they are ready and able, as Eleanor puts it, to “live a life of my own in a place of my own the way I’m supposed to.” They do not always readily acknowledge the nature and degree of support they need to secure and retain competitive employment, but they invariably know that the sheltered work settings so often recommended for them will not provide either the income or independence they desire.

- *Personal career and life planning activities provide survivors with a holistic and flexible approach to addressing their multiple and complex needs over an extended time period.* The planning process recognizes the fact that survivors cannot address their VR needs without addressing needs in other areas, some of which they want to meet first. Most people entering Project CIRCLE have become isolated while recovering from their injuries and, like Andrew, want first and foremost just to get out in the community. Some have pressing sensory, physical, and/or medical needs which have not been addressed because insurance coverage has run out and they have no money to pay for services. Some need to work on maintaining their sobriety, while most continue to have difficulty acknowledging and accepting their residual and altered capacities. Although wanting to work, most are not sure of what they want to do or what they can do. The personal career and lifeplan addresses all these needs, but the implementation sequence and timeframe vary considerably from individual to individual.

- *The circle of support provides an active role for survivors and family members in the career and life planning process.* In many

cases, survivors and family members must overcome the feelings of helplessness and hopelessness which often accompany the prolonged period of recovery, heavy dependence on clinical opinion, and less-than-desirable outcomes associated with brain injury. The circle of support gives them “permission” to dream again about a career and a life in the community. The circle facilitator provides them with assistance and support in making choices, taking action, learning from mistakes, and taking control of the rehabilitation process. As Andrew’s story indicates, putting the survivor in the driver’s seat is not always easy and sometimes the motivation to take charge comes from serendipitous events. But personal choice and control are essential to individual change.

- *The identification, assessment, development, and use of residual capacities and compensatory strategies in real world settings are essential to the rehabilitation process.* For many reasons, survivors and those close to them are more aware of the deficits resultant from their injuries than their residual capacities, that is, the body of skills, knowledge, feelings, attitudes, and supports they have retained from before their injuries. Recognition of and building upon these capacities by the individual and his/her circle of support is a key strategic component and important motivational factor in the rehabilitation process. Just as important is the development and use of compensatory strategies to address deficits, whether with regard to cognitive functions, sensory abilities, motor coordination, communications capabilities, or mobility. Survivors often work on developing residual capacities and compensatory strategies in clinical settings isolated from the people and places of their everyday lives. As the stories of Eleanor and Andrew illustrate, circle members can help to extend knowledge and reinforce use of these capacities and strategies in an increasingly efficient and effective manner within real world settings—at work, at home, and in the community.

- *Survivors’ vocational capacities and needs should be identified and addressed*

*earlier in the recovery and rehabilitation process.* Both Eleanor and Andrew performed volunteer work in residential treatment facilities, but it was regarded more as therapeutic than vocational activity. Given such experience and the strong desire of those served by Project CIRCLE to return to work, it seems both feasible and desirable to begin career development and job exploration activities sooner in the rehabilitation process to facilitate earlier decision making in this regard. This would precipitate the marketing and job development activity required to more immediately match survivors to employment opportunities upon their reaching the levels of cognitive, sensory, physical, and emotional competence needed to initiate re-entry into the competitive job market.

- *Unpaid and volunteer work experience provides survivors with opportunities to further explore career and occupational options and gradually increases job-related competence and confidence.* As already noted, survivors seldom know what they can do or want to do. In addition, they have had little experience in exercising residual capacities and compensatory strategies in real work situations. Further, they often lack confidence in both their social and performance capabilities. Support in unpaid or volunteer work experience situations provides them with a relatively safe and nonthreatening opportunity to address needs in all three areas, but within the real work world. For many survivors, such as Eleanor, such work experiences provide a gradation of small steps for achieving modest goals which appear to be essential for successful re-entry into the competitive work force. Moreover, as also illustrated in Eleanor’s case, unpaid or volunteer work experience usually works best when employers use it as an opportunity to explore, assess, and determine their capacities for supporting the employment of survivors.

Having learned these lessons over the first half of Project CIRCLE, we have already formulated and begun to enact strategies which will:



- increase the number and quality of working referral and service partnerships we have with hospitals, facility-based programs, and case management companies that serve survivors during the inpatient and early outpatient stages of the recovery process, thereby introducing career and job exploration activities earlier in the process;

- establish and maintain a project support group, with the help of a mental health professional, to further assist survivors and family members in acknowledging and addressing the psychological and emotional challenges associated with surviving a head injury or being close to someone who has;


- retain and make use of services from a cognitive therapist to further assist project staff and consumers in identifying and developing residual capacities and design and use of

more efficient and effective compensatory strategies;

- strengthen our emphasis on the development and use of circles of support by recruiting additional family members, friends, and coworkers as members and making more use of workteam circles at employment sites; and

- through a recently established business advisory committee, broaden and deepen private sector involvement in the development and realization of more varied and remunerative job opportunities for survivors of head injuries.

Utilization of these strategies is intended to expand and enhance the roles of survivors, professionals, family members, employers, and other natural supports in the vocational rehabilitation planning and implementation process and thereby provide survivors with employment situations

which are even more conducive to clarifying and eventually achieving their career goals and lifestyle dreams. 

## Notes

1. As told by Diane Wheatley, who works with "Eleanor" as her employment specialist.

2. As told by Michael Dunfee, who works with "Andrew" as his employment specialist.

Project CIRCLE is operated by ICON Employment Services of Alexandria, Virginia, in cooperation with the Virginia Department of Rehabilitative Services under grant award number H235G20020 from the Rehabilitation Services Administration, Office of Special Education and Rehabilitative Services, U.S. Department of Education.



## Switzer Fellowships Announced

The U.S. Department of Education announces the availability of research fellowships in the fields of disability and rehabilitation. The fellowships, to be administered by the Department's National Institute on Disability and Rehabilitation Research (NIDRR), are on two levels:

- *Distinguished Fellowships* are awarded to individuals of doctoral or comparable status who have 7 or more years' experience in relevant research areas.

- *Merit Fellowships* are given to persons in earlier stages of their research careers who have either advanced training or experience in independent study in appropriate areas.

Successful applicants will conduct research into the effects of disabling conditions on the lives of people with disabilities, ways to improve the delivery of rehabilitative services, or difficulties encountered in conducting this kind of research. The fellowships cover a 12-month period and provide a stipend and an allowance for research related expenses, including travel.

Applicants will be evaluated on the quality and level of their formal education, pertinent experience, and the recommendations of present or former supervisors or colleagues. Of particular interest are comments regarding the applicant's ability to work creatively in scientific research. The application, which must not exceed 12 pages, must contain:

- an explanation of the importance of the research target to the mission of NIDRR;
- the research hypothesis, objectives, and methodology; and
- assurance of the availability of necessary data resources, equipment, and institutional support.

The fellowship program was announced in the *Federal Register* of June 3. The deadline for submission of applications is November 15, 1994.

Applications should be mailed to: National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, 330 C Street SW, Washington, DC 20202-2572. Telephone: (202) 205-9143





# Approaching Zero Exclusion: The Role of Positive Behavioral Supports in Community Employment

Cary Griffin  
Joan Sweeney

**J**anet spent her adolescence and early adult life in an institution for individuals with severe developmental disabilities. The national movement toward deinstitutionalization offered her the opportunity to move to a small Colorado town. The move did not, however, eliminate the violent behaviors for which she was known. Within weeks, she had attacked other consumers, caused serious injury to staff, and had inflicted multiple wounds upon herself. The rehabilitation agency that served Janet does not believe in the use of restrictive procedures in controlling behaviors, but because it did not have training in functional crisis management techniques it returned her to the institution.

After several months, she returned to her new community and the staff explored a community-inclusive approach to meeting her needs. Through the development of a person-centered *Career Plan* and the development of a *Plan for Achieving Self Support* (PASS)<sup>1</sup> through Social Security, a nationally recognized nonaversive behaviorist was hired to analyze possible causes for her behavior and to explore possible interventions to minimize violent acts. Because Janet was new to the community and had been separated from her family for most of her life, there were few functional clues to explain some of her behaviors.

The approach evolved to one of exploring options that would provide more efficient ways for Janet to get her needs met, be they the need to be alone or have physical space, the need to con-

trol her daily life choices, or the need to feel comfortable with her new surroundings. Although she carried a label of severe mental retardation and used little verbal communication, she made it known that she wanted to spend time in well-lit areas and that she had an interest in arts and crafts.

The practice of functional assessment of behavior maintains that there are reasons for particular behaviors; that even with organically rooted behavior, the environment shapes actions into understandable forms. The challenge in supporting behavior change comes in restructuring or changing the environment to allow more efficient means of getting what a person desires, or teaching replacement behaviors that accomplish a task and satisfy a need. This approach differs from typical "extinction" methods; the assumption being that new, more practical skills naturally eliminate the need for the old, bothersome behavior. By considering Janet's interest in well-lit places and her artistic desires, a job search was begun.

A company was located in the small town that manufactures textile products, such as baby bibs. The agency job developer and David Hammis, a staff member of the Center for Technical Assistance and Training (CTAT), performed a thorough job analysis and discussed with the owner the possibility of employing Janet. The employer said he could use another seamstress, but Janet had few sewing skills. With the use of the PASS, however, a computerized bar tacker was purchased that Janet could operate. After more than 2 years, Janet has evolved into a valued employee; she is friends with several coworkers; and she performs sewing, trimming, and silk screening

jobs for the company. She converses openly and is no longer violent.

When videotapes of Janet are shown in training sessions, the participants, unaware of her past, describe her as "moderately disabled," "pleasant," and "hard working."

Janet changed because her situation changed. Through the person-centered career process, she was taken seriously, and her desire to explore personal interests in artistic work led to her employment and the improved quality of life that is crucial to behavior change.

Many stories similar to Janet's are being heard throughout the United States and other countries. The progression towards supported employment, community integrated and individualized service/support, and the new emphasis upon school-to-adult life transition is making it necessary to rethink professional, parental, and consumer definitions of accomplishment. Still, CTAT's work nationally recognizes that persons with severe, challenging, and puzzling behaviors (such as violence, stereotypic, physical regulation, self-stimulation, screaming, pica, avoidance, et al.) are not leaving segregated settings for community jobs and individualized housing. In response, CTAT applied to the Rehabilitation Services Administration (RSA) to establish a Special Demonstration Project to teach a select cadre of professionals how to better support citizens with severe disabilities in real jobs of their choice. *The Regional Employment Through Positive Behavioral Supports Project* (ETPBS) was designed "to address the establishment of supported employment for persons eligible for such services, who also have an



identified challenging or excess behavior which is the primary historical cause of their unemployment."

***Nationally, supported employment for persons with severe disabilities who also have puzzling or challenging behaviors has met with limited success.***

## Program Components

ETPBS is designed according to the principles of human resource development, which recognizes that working professionals need training and consultation that is directly applicable to their daily work. In order to accomplish this functional learning approach, CTAT staff provides onsite assistance and training for a 1-year period to agencies selected for the program after applications are reviewed by a committee of consumers, families, professionals, business people, and the vocational rehabilitation central offices in each of the region's six states—Colorado, Montana, South Dakota, North Dakota, Wyoming, and Utah.

Each site identifies a minimum of five persons with behavioral labels that have kept them from being considered for supported employment. Support teams comprised of the consumer, staff, family, neighbors, and other citizens are established to identify the function of the behavior, analyze key quality of life concerns, and develop career plans with adequate, nonaversive supports that will help the individual become employed. These core teams receive regular training and consultation following thorough needs assessments and interviews. Training topics typically include: functional analysis, job creation/job carving, personal futures

planning, Social Security Work Incentives, environmental analysis, community organizing, and a variety of non-aversive approaches for redirecting and replacing behaviors.

## Guiding Values

Nationally, supported employment for persons with severe disabilities who also have puzzling or challenging behaviors has met with limited success. ETPBS was established based upon the extensive body of research related to behavior change and upon field experience collected by CTAT staff in their current consultative roles and as former direct service practitioners, from consumers, from families, and from rehabilitation personnel throughout the United States. The first step in approaching the establishment of career opportunities lies in the formulation of sincere beliefs. ETPBS is founded upon guiding principles that define service delivery from both a direct service and an organizational standpoint. It has become clear that efficacious frontline habilitation techniques are critical to proper consumer-directed service delivery, but often overlooked is the role of leadership in human service and rehabilitation agencies. Organizations must be values-based at all levels, and policy and procedures must be established that allow power to flow from individuals receiving services to the professionals who facilitate community supports (Griffin, 1994). Without this consumer-control focus, atypical outcomes, such as community inclusion for individuals with multiple and severe disabilities, do not occur (Lawhead, 1994). The first step towards inclusion begins with open examining, internalizing, and operationalizing of the following:

*Zero Exclusion.* The direct service implication is that all people, regardless of severity or type of disability have the right to live, work, and recreate in integrated settings in their chosen community. Operatively, holding true to this principle requires elimination of the concept that individuals have to get ready to work. Utilizing this guiding

principle, it is understood by staff and consumers that all people *are* ready to work. The tough part is figuring out the people, places, and things that will assist them in being successful and how to acquire those supports.

The organizational implication is that systems must, in all aspects, respect the fulfillment of this belief, and management actions should direct the replacement of congregate/segregated facilities with options based upon consumer desire and the presence of people without disabilities. Further, the organizational implication contains the directive that all consumers and staff must be involved or have a true representative voice, regardless of position, in agency decision-making, planning, and operations.

In one ETPBS site in a small town in Utah, individuals recently deinstitutionalized were placed in a segregated day-activity program. These persons were considered "too disabled" to participate freely in the life of the community. But, over time, supervised trips were made into the center of town. Soon, these individuals left the program to visit downtown alone or in pairs. Concerned citizens phoned the program to voice their care and concern. The callers were thanked for their cautiousness, but were assured that everyone was safe. Within months, the community fully accepted these new citizens and two were offered jobs with the city maintaining flower beds and other accoutrements on Main Street (Simon, 1994). Had the program emphasized readiness instead of *zero exclusion*, these individuals would still be working on life skills in a classroom tucked safely away from interactions with typical adults.

*Partial Participation.* The direct service implication is that all people have something or some part of something that they can do and enjoy doing. It is our job as professionals to see that this

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“spark” or skill is utilized to begin the development of real work and/or civic involvement. It also holds true that staff must be allowed by the organization to utilize their strengths and creative talents in supporting individuals with excess behaviors (Hammis, 1993).

Partial participation holds that, in career development or in understanding behavior, success is found in moving towards strengths and enjoyments that currently exist, rather than training towards a predetermined job, role, or behavior. Using this values tenet as a guide, for instance, the lead author once helped establish a job for a young man who was quite violent. “Roger” was in a day-activity program and indicated he was extremely bored. He loved working with his hands. In fact, he was very competent with hand tools and enjoyed dismantling mechanical apparatus. He once took apart the kitchen plumbing in the house he lived in. The problem was that he could not put things back together too well and he actually had little interest in returning machinery to working condition.

His behavior was viewed as destructive and he was further segregated from the community for fear he might destroy property belonging to neighbors or local businesses. This restriction led to more frustration and the violence escalated. A forward thinking employment specialist called the CTAT offices, and consultation concerning the functional assessment of Roger’s behavior began.

The obscure became obvious. The problem was not with Roger. The problem was the restrictive intervention designed by staff. There seems to be a natural tendency for human beings to react to “noncompliant” behaviors with punishment or restriction. Roger suffered from such an intervention. Instead of beginning by asking “What can we take away from this person to control them?” we must learn to ask: “What can we help this person get more of? What will make this person’s life better? What is this behavior telling us? What competencies are represented by this behavior?” By approaching Roger’s situation in this way, a job was

sought for him at an auto wrecking yard. His first community job involved removing carburetors, bumpers, starters, and alternators from junked cars. As an added bonus, Roger was so tired at the end of the day that fighting with others became less desirable than relaxing in front of the television.

*Zero Instructional Inference.* This principle holds that for most people, with or without disabilities, the place to learn is in environments where the target skills will be used. Therefore, the practice of readiness (developmental continuum) and earning the right to a job or social activity is eliminated based upon solid evidence that preparatory training typically has little validity, especially when intellectual or behavioral disability is encountered.

Most of us did not learn how to do our jobs in high school or college. We learned perhaps to think, reason, and gather information, but the actual business of “doing our job” was learned by performing that job. The idea that “prevocational” training in a classroom or segregated facility gets one ready is largely fallacious. Considering that most individuals lose their jobs based upon the appropriateness of human interaction and that the only way to learn how people interact is to be around people, people of diverse backgrounds, the need for organizational emphasis upon facilitating community-based learning environments becomes clear. Parents seldom rehearse social skills with their children. Children learn social interaction by socializing. Changing behavior often demands the witnessing of how others behave in similar situations; and this modelling often takes a great deal of time due to the unlearning and relearning necessary for behavior change. There is no quick fix to behavior or education.

*Mutuality.* This concept implies that we must at all times attribute thinking and feeling to people with disabilities, regardless of type or severity of disability. Many times we hear staff describing an individual’s behavior as “attention seeking” in design. Rather than trying to increase the amount of attention the individual might receive in

healthy, natural ways, staff have typically been taught and encouraged to ignore the attention seeking behavior. Usually, the assumption is that the individual is already getting more attention than most people. What is often forgotten is that many people with disabilities, particularly those who were institutionalized, have never had their emotional needs met, and maintain “black holes” of emotional need. What seems like a lot of attention to us is barely enough to begin addressing typical human needs.

The golden rule should be strictly enforced in all interactions with people with disabilities and their friends and family. The organizational implication is that policies that restrict individual freedom, allow aversive and cost/response-based behavioral interventions, allow the hiring of ill-equipped staff, or continue to promote segregation in its many forms are no longer tolerated. Further, mutuality means that staff, especially those closest to the customer, are well-respected, well-paid, well-educated, and involved to such a degree that they truly provide world-class service. If frontline staff are viewed as expendable, and pay and training investment statistics show this to be a nationwide situation (Kiernan & Schalock, 1989), they are probably not prepared or motivated to assist individuals with excess behaviors in reaching their dreams.

*Interdependence.* The crux of creating community employment for individuals with excess behaviors lies in the interconnectedness of consumers, staff, and organizations. For far too many years, people with disabilities have been restricted politically, economically, and physically from interacting with “typical” citizens. CTAT’s field work also reveals that many professionals are socially isolated and are, therefore, unaware of the capacity for support from the community; and that the image of many rehabilitation organizations as being apart from the rest of community life—as witnessed in charity/pity-focused fundraising and the low visibility afforded the rehabilitation process in segregated programs—



only adds to the social isolation and subsequent impoverishment of individuals served.

***When typical human interaction is denied, excess behaviors occur.***

While personal medical and health-related issues are always a starting point for investigating the cause and resolution of excess behaviors, quality of life concerns—largely based upon the opportunity for diverse human interactions—appear to be extremely critical in the majority of cases known to CTAT. Most of us rely upon a social network for support in our daily lives. When we have decisions to make or successes to share, we interact with others, generally those of our choosing. Individuals with severe disabilities often have no social network other than paid professional staff. When typical human interaction is denied, excess behaviors occur.

For example, “Jim” grew up in a small town in South Dakota. He lived with his mother all his life, attended special education classes in the public school, and had the freedom to roam around town by himself. All the shop owners, post office employees, and library personnel knew him well and spoke with him frequently. When Jim turned 30, his family and the system decided it was time for him to move out of his mother’s home. Rather than moving him into his own apartment, with support, in his home community, he was moved 80 miles away to a larger town. He is currently living in a large group home and working in a sheltered workshop. Staff are witnessing many behavioral changes, including violence, withdrawal, isolation, depression, and noncompliance. He no longer goes anywhere alone, has little personal privacy or freedom, and has lost all the connections that had provided friendship and support in his home community. The natural process of interdependence facilitated his membership at home; a bad management decision, based upon sys-

tem convenience and a disavowal of Jim’s fundamental right to live, work, and recreate in his place of choice, has created behavior issues that now jeopardize his standing as a citizen and will possibly end up costing the system more in resources than if no intervention had occurred.

To create social networks, the ability and opportunity to be in a variety of environments with a variety of other people is important. Eventually, a few acquaintances become friends and quality of life is increased through the interaction that results (Oldenburg, 1989). Our friends, families, coworkers, and acquaintances teach and support us. Rarely can individuals meet their needs alone. Unmet needs manifest themselves in many ways. Often, the loneliness felt by people with disabilities results in behaviors that bring rapid attention from those in view. The inability to communicate needs certainly causes frustrations that result in troubling behaviors; and being placed in situations where the urgency of one’s needs are not acted upon—either due to a lack of funding or lack of staff technical knowledge—certainly fosters atypical behavior. The bottom line is this: if human beings do not have choice, power, and control in their lives, their behavior will reflect their frustrations. For persons with disabilities, adding a behavioral label to a primary disability label often results in more segregation and still fewer opportunities. ETPBS is attempting to focus attention on how we—as rehabilitation professionals—provide necessary supports and—as “detectives”—seek positive clues for the use of existing talents, regardless of how obscure or seemingly inconsequential those talents may appear.

### **Person-Centered Planning.**

Identifying available, affordable, and appropriate supports for individuals with challenging behaviors is often time-consuming and difficult. ETPBS emphasizes that many of the supports necessary for success on the job and at home are already found in the com-

munity, but that these options are seldom developed by or for individuals with disabilities. Typical behavioral interventions rely upon extinction of behavior through cost-response or punishment methods. This is a typical model we have all witnessed, such as when a parent instructs a child to “take out the trash or you don’t get your allowance.” ETPBS emphasizes asking first why I might not wish to take the trash out, concerns itself with whether this indeed is a necessary activity at this given time and place, and explores other means for accomplishing or circumventing the task. Above all, getting into power struggles with people is always avoided and healthy, mutually beneficial learning environments are developed by first focussing on those tasks we know to be essential in life. ETPBS concentrates on the belief that most behaviors, with proper study, can be explained or at least better understood and that the best approach to integration of folks with seemingly aberrant behaviors is to put them in environments where these actions are no longer necessary or where new, more efficient behaviors can be learned.

In determining what tasks are essential, it is more important to ask the individual and the family, rather than to consult a rehabilitation curriculum that presupposes what is important to all people with a particular disability. ETPBS serves individuals with various disabilities, such as Down Syndrome, psychosis, brain injury, sensory impairment, and autism. Utilizing a person-centered approach minimizes the emphasis typically placed upon disability type and instead focuses upon the person, the necessary social network, the employment choices, and the various explanations for or uses of a particularly challenging behavior.

A review with staff, the consumer, available family, and volunteers or interested citizens is undertaken to identify key life issues and quality-of-life needs. These meetings typically last several hours and may be held weekly, monthly, or as often as necessary, or possibly until the individual decides they are no longer necessary. Behav-



iors are discussed and career plans are developed and revised based upon consumer desire. Staff and others receive training during the first several months of the planning process. Through the development of a series of life maps revealing personal history, dreams, preferences, friend/family supports, health status, etc., graphic information is revealed that allows the team to identify possible causes of inappropriate behavior, the absence of ingredients that could enhance enjoyment of life, and clues to aid in identifying vocational interests and strengths. Important in this mapping process is the identification of those things that do not work for a particular person and the restructuring or reprogramming of environments to eliminate such life irritants.

By listening to the consumer and family—rather than judging and guessing—quality job development has resulted and prompted the establishment of ETPBS. For example, one young woman accused of “noncompliant” behaviors was dismissed from a program because she lost several jobs. Upon listening to her and her parents, it became clear that she needed to work around others, have a variety of tasks to perform so she did not get bored, and be able to recreate with coworkers on an afterhours sports team. This listening led to a job for the consumer with a Fortune 500 insurance company that provides her with a variety of tasks in several departments. When she and her job coach arrived, there was no sports team; now, there is a bowling team, and the job coach’s role has faded and been replaced by assistance from her coworkers, who teach new tasks as necessary.

Another emphasis of person-centered planning is upon the seeming lack of motivation to work, of which some people with disabilities stand accused. In one case, a middle-aged gentleman was referred to a day-activity center and deemed ineligible for work due to his label of “severe” mental retardation and lack of interest in work. After spending time with this person, the job developer noted that the words, “horse,” “cow-cow,” and “NO,” were


spoken often and were, in fact, the only words the man spoke.

Using this language as a clue, businesses related to farming and farm animals were explored. At present, the owner of a riding stable has agreed to hire the individual as a stable hand and, to supplement his income and create a capital investment, a PASS was developed and approved for an Arabian stud horse to be owned by this man, launching his career as a horse breeder and career capitalist.

The process is simple but requires listening and creativity.

## Conclusion

People with severe disabilities, their families, friends, and professionals are raising their expectations. Partnerships are being formed to release service consumers from continuums of care and the traps that artificial labels create. The Rehabilitation Act Amendments of 1992, the Assistive Technology Act, the Americans with Disabilities Act, and other major pieces of legislation are establishing community referenced guidelines for the improvement, expansion, and normalization of lives and opportunities. Individuals with challenging, excess, and puzzling behaviors must also have their rights guaranteed. ETPBS is one effort aimed at realizing full citizenship for individuals with disabilities.

In the coming years, monographs, a field-based training video series, and journal articles will be produced for consumers, families, and professionals to assist in the training and adaptation of nonaversive behavior strategies. The Center for Technical Assistance & Training, located at the University of Northern Colorado, also offers telephone and onsite consultation on positive behavior support, as well as training programs, a free lending library, and a free newsletter, *The Field Report*. CTAT hopes to eventually expand ETPBS nationwide, after field work has refined the various, individualized approaches now being explored. 

For more information concerning ETPBS and other CTAT programs, in-

cluding comprehensive supported employment training, person-centered planning facilitation, organizational development, and leadership training, call (303) 351-6895 or write: Center for Technical Assistance & Training, University of Northern Colorado, Greeley, Colorado 80639.

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## Note

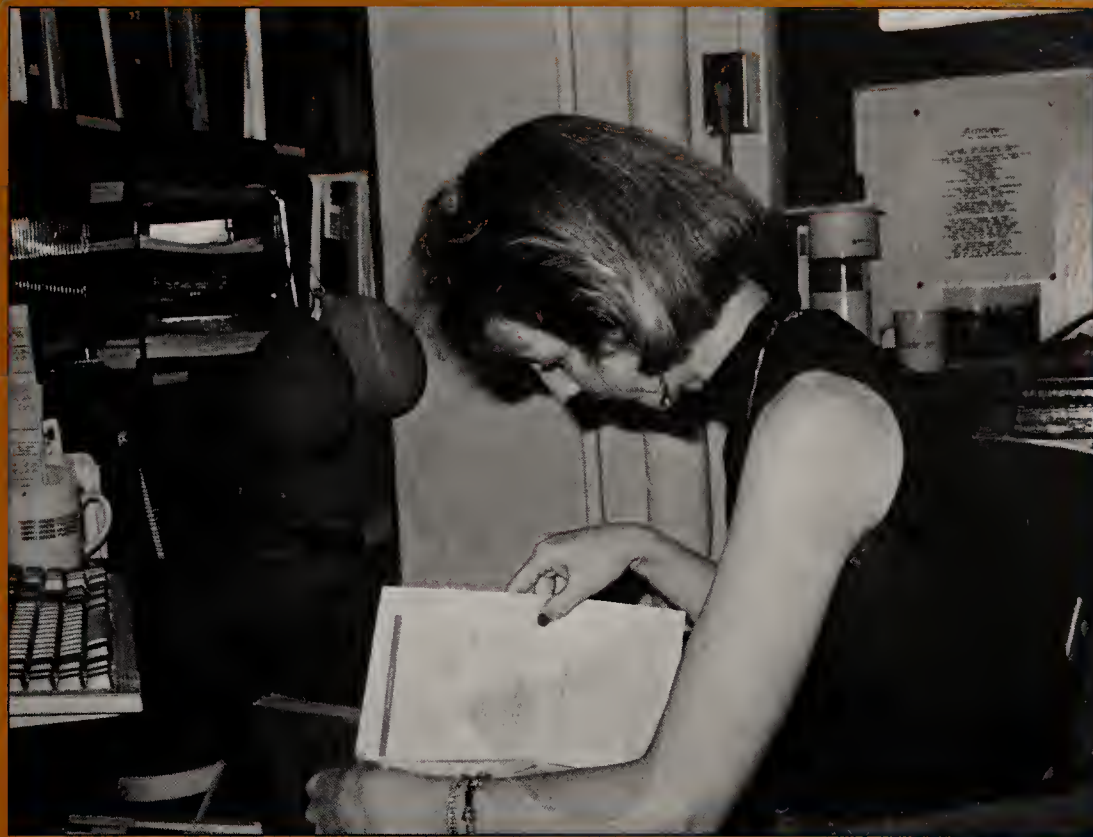
1. A PASS Plan, or Plan for Achieving Self-Support, is a Social Security Work Incentive that allows a Supplemental Security Income (SSI) recipient to set aside money for a specified period of time for the purpose of accomplishing an employment goal (Prero, 1993; Social Security Administration, 1988).

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# Improving Transition Outcomes for Persons with Specific Learning Disabilities



*Susan Waldo, school psychology doctoral intern, reviews test results.*

*James R. Koller, Ph.D.*

Most people would agree with the basic assumption that one goal of education is employment. Yet, the problem of securing gainful employment for the regular high school student, let alone college graduate, is becoming more and more difficult. Likewise, for persons with substantial impediments to employment, such as specific learning disability (SLD), a positive vocational outcome is far from guaranteed, even with appropriate vocational planning.

Since the enactment of Public Law 94-142 in the mid-1970's, SLD has continued to receive increasing attention from both a research and service perspective. More articles and research studies have been published in the last 7 years than in the previous 25. However, until the early to mid-1980's, the primary focus was upon the person's

academic problems resulting from SLD; the impact that SLD would have on employment was not often considered. In point of fact, it was assumed by many that the individual's functional limitations associated with SLD were often considered irrelevant or were ignored completely in the non-academic, adult world of employment (Berkeley, 1989).

With the realization, however, that kids with SLD grow up to be adults with SLD, the Rehabilitation Services Administration (RSA) convened a national task force in the early 1980's to investigate how people who have this impediment to employment could be better served through the state-federal vocational rehabilitation (VR) system. As a result, SLD has been recognized as a category eligible for VR services only since 1985, when RSA adopted its formal definition of this disabling condition (RSA, 1985).

While considerable time, money, and effort have been expended by con-

cerned parents, schools, and various state and federal agencies, positive transitional outcomes for many people with SLD leave a lot to be desired. People with SLD are often unemployed, underemployed, and significantly at risk to drop out of school or for subsequent job failure (Berkeley, 1989; Tillman & Abbott, 1992). According to RSA, SLD

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continues to represent the fastest growing impediment to employment (Mars, personal communication, 1993). Thus, concerted efforts related to self-advocacy and those expended on behalf of the individual with SLD become increasingly important as individuals go from school to work, job to job, from school to postsecondary education, and from school to independent living.

Various SLD models exist for the provision of transition service delivery, but the comments and recommendations that follow reflect observations from our RSA grant project and participation on the RSA Commissioner's SLD Workgroup, as well as VR training and consultation conducted primarily in RSA Regions VII and X.

## Disability Complexity

The needs of individuals with SLD in transition are compounded by the fact that learning disabilities, while officially categorized by service delivery systems as a single disability category, are essentially heterogeneous in nature. Thus, individuals display a wide permutation and combination of SLD types, including abilities and deficits. It is not enough, then, to say a person is just "SLD." What type or types? SLD for what? As a result, the diagnosis and subsequent service delivery provisions need to be individualized to effectively meet the specific needs of the person. To assume that all individuals have the same problem and then to provide similarly for each is archaic and will only postpone or stop progress in transition.

It is also important to recognize that SLD manifests differently, whether in the classroom or on or off the job. We consistently encounter consumers, parents, and, surprisingly, rehabilitation and school personnel who remark "If he/she can only graduate, get out of high school and get a job, then he/she will be OK" or "relax, your child will outgrow it." Concerted effort must be undertaken to eradicate the notion that the disability will somehow go away. Graduation from a public school, or a vocational-technical training program for that matter, will not guarantee suc-

cess. On the other hand, sufficient evidence is accumulating that SLD deficits, regardless of severity, can be effectively accommodated to enable the individual to live a meaningful, productive life. (Ginsberg, Gerber, & Reiff (cited in Gerber and Reiff, 1994)).

## Conflicting Definitions

Major differences exist between various definitions of SLD, e.g., educational and vocational, thereby directly affecting not only the diagnosis but also subsequent placement and service provision. For example, it is understandable that public schools, who represent children and adolescents, typically follow more of an educational model that centers around deficits related to the academics. Agencies, including VR, however, typically follow the RSA definition which is more encompassing, relates to adolescents and adults, and has wider ramifications, especially in regard to employment and independent living. However, given the fact that secondary schools represent the largest single referral source for VR applicants with SLD (Berkeley, 1989), it is important to recognize that VR and special education mandates also differ. State VR agencies screen applicants based upon several factors, including:

- the documentation of the impairment,
- that it represents a significant impediment to employment, and
- that services are required for the applicant to be successful as he/she enters employment.

It is not unusual, then, to see major difficulties when schools do not understand the VR mandate and assume that any student eligible for special education placement is automatically eligible for VR services. A number of problems, including hurt feelings, could be avoided if both sides would clearly understand each other's position until a more unified and solitary operational definition could emerge.

Differences between the public schools and VR also exist relating to the theory and practice of remediation and accommodation intervention. All

individuals concerned, including parents, need to realize that the primary focus in special education is on curricular remediation, which is a method of compensation designed to internalize the learned skill, while VR looks to primarily establish effective accommodation or circumvention strategies that eliminate barriers to employment. Essentially, accommodation is a method of compensation in which an externally imposed system or device enables a person to accomplish a given task (Bencomo & Schafer, 1984). The point, however, is that the primary intervention focus by VR is not on remediation.

*Perhaps no single factor has potentially as great an influence on a positive educational or vocational outcome as does a clear determination of the problem or diagnosis itself.*

## Establishing the Diagnosis

Perhaps no single factor has potentially as great an influence on a positive educational or vocational outcome as does a clear determination of the problem or diagnosis itself. To aid in identification, school systems often follow a discrepancy or disparity model, which is the application of a statistical regression formula applied typically between cognition and achievement. Essentially, given certain exclusionary factors, e.g., the disability is not due to emotional disturbance, mental retardation, etc., it assumes that SLD exists when there is a significant difference between mea-



sured individual intelligence (e.g., WISC-R or WAIS-R tests) and achievement (e.g., PIAT-R, W-J, and other tests). It is important to note that the school's multidisciplinary team may also document, through procedures involving informal assessment, that a significant discrepancy exists even though the deviation is not statistically significant. It is not unusual, however, for well-intended school personnel to place struggling students in SLD services who do not fit in the regular classroom and who do not meet the intent of a psychological processing disorder (e.g., slow learner, etc.). State VR agencies, on the other hand, follow the DSM-III-R diagnostic system and must recognize not only the discrepancy or disparity that exists between cognition and achievement and its effect in the classroom, but significant deficits across all areas of psychological processing as it impacts on the world of work. This includes memory (auditory, visual, short-term, long-term, etc.), visual/spatial and verbal/auditory reasoning, coordination, social competence, and emotional maturity. Further, it is important to recognize that diagnosticians at all levels must not look only for the presence or absence of SLD but also for different types existing concurrently, their frequency, severity, and duration. While special education and VR definitions and mandates differ, it is important for all to effectively communicate on behalf of the consumer; otherwise, the consumer suffers. Interrelated factors such as turf issues between special education and regular education, well-intended but misguided parents, inability to access the VR system, inconsistency between theoretical and formal state agency definitions and their operational practice, communication problems between all parties involved, the person's denial of the disability, and mechanistic Individualized Education Plans and Individualized Written Rehabilitation Plans (IEP's and IWRP's) further exacerbate the problem.

While a complete psychoeducational assessment is essential across all areas of development, it is as important to recognize an individual's strengths as it is



*Karen Dunham, school psychologist, evaluates cognitive, educational, personality, and vocational factors for consumer.*

to identify his/her weaknesses. Vocationally, it is often possible to accommodate to a person's deficits by fully exploiting his/her strengths. Clearly, while educational and rehabilitation personnel alike need to look at "what is right" as well as "what is wrong" with the individual, rehabilitation counselors need to break the typical "medical model" approach in looking only to establish functional limitations for eligibility determination. How often do we encourage consumers to openly discuss their strengths or divulge positive accommodative strategies they have found to work? Again, is not sustained and meaningful employment one of the goals of education?

Further, is it not time that we realize that SLD also exists outside the domain of average intelligence? For example, we consistently see reports by various professionals—including school personnel and rehabilitation consultants—stating that you cannot have both SLD and gifted intelligence. With advances in measurement and developmental theory, methodology (including medical and neuropsychological instrumentation), research, and practice, is it

not possible to assume that SLD exists in less than average intelligence (e.g., borderline) as well?

While the historical and traditional focus on the assessment of SLD lies in standardized psychometric procedures, we must not be so inflexible as to fail to recognize the importance of authentic or functionally-based assessment, work samples, and observations from consumers and significant others.

All diagnosticians and service providers (including parents) must recognize the increasing evidence demonstrating corollary psychosocial adjustment problems existing concurrently with SLD (Grasso & Price, 1992). Nearly one-third of a sample of SLD prospective persons referred to determine VR eligibility received DSM-III-R diagnoses (e.g., mood disorders, etc.) along with a primary diagnosis of SLD when independently evaluated by licensed doctoral psychologists (Lapan, Koller & Holliday, 1991). Clearly, it is not enough to identify a type of SLD without knowing corroborative personal, social, and emotional strengths and weaknesses. Ultimately, the person's ability to get a job may relate to the type of SLD, its de-



gree, and accommodation; however, the person's ability to sustain and keep the job often appears to rest as well in his or her own personal/social/emotional functioning.

## Situational Assessment

Perhaps the most fundamentally pragmatic objective of the entire assessment process is the determination of the individual's actual functional ability (again, both strengths and weaknesses) related to a context of real life demands. Procedures such as the administration, scoring, and interpretation of standardized as well as clinical psychoeducational instruments by competent professionals represent a valuable tool in the development of hypotheses or inferences concerning real life performance. However, it is not just the derivation of scores that is important, but a clear understanding of what skills and abilities make up those scores related to the accomplishment of real life educational and vocational issues that is necessary. And, while research evidence suggests an increasingly positive correlation between the individual's performance on these procedures and real life circumstances (McCue cited in Gerber, 1994), gaps continue to occur in accurately predicting behavior. For example, higher order cognitive (executive) skills or specific personality characteristics essential to the satisfactory completion of complex daily tasks are often difficult to measure directly. Nonetheless, reasonable hypotheses can be generated from these procedures and then directly tested in a more functional or situational assessment (SA) setting. With the addition of SA to both clinical and standardized psychometric assessment, including all available school information, the individual's functional job skills can be observed by placing him/her directly on a specific job of interest, thus allowing for the opportunity to observe how the deficits manifest in the natural environment. This also presents an opportunity to develop more realistic job accommodation strategies that can be directly field tested.

*Situational assessment is an ever-evolving, dynamic evaluation . . .*

Situational assessment is an ever-evolving, dynamic evaluation involving the placement of an individual directly on a real world job, not in the typical vocational evaluation or contrived work sample laboratory. As a process, SA generally consists of four broad phases:

1. *Specific Job/Task Analysis.* Utilizing the format suggested through the use of *The Revised Handbook for Analyzing Jobs* (1991), each job task is analyzed for potential strengths and weaknesses identified in the psychoeducational evaluation and the review of school records, including teacher comments. This allows the evaluator the generation of more realistic strategies to meet the specific needs encountered by the individual in real life.

2. *Job Teaching.* A job coach teaches the job tasks to the person being evaluated and assesses each task directly as it is performed. When the task has been determined to be a functional limitation (unable to be performed the standard way), a strategy or job accommodation is developed and observed. The most important source of accommodation strategies is the consumer, while the job coach assists in the generalization of skills to other areas.

3. *Development of Accommodation Strategies.* The strategies developed are taught directly to the consumer for self-implementation to meet job performance standards. The use of assistive technology, job restructuring, and adap-

tive teaching strategies are often found to be beneficial.

4. *Empowerment.* Through guided and repeated practice coupled with positive reinforcement, the consumer gains in confidence and his/her performance on the job can then be videotaped for use by the rehabilitation counselor, school personnel, employer, and the consumer for continued vocational planning, job placement, and self-advocacy.

Thus, SA allows for the establishment of individually designed strategies to test specific daily vocational job duties found in the natural environment. By directly placing the individual in a real job, the opportunity to observe him or her in a real world environment over an extended period of time provides the best measure of future job success.

## Career Expectations

For individuals with SLD in transition from school to work, problems abound regarding the appropriateness of individual career goals and job expectations and a general lack of career maturity. This problem is a pervasive and often debilitating concern affecting not only the consumer, but significant others (e.g., parents, and employers) as well. Often, due to a lack of real world work experience, direct exposure to various jobs, labor market uncertainty, notions that "you can be and do anything if you just try hard enough," students in transition often do not, even remotely, consider or know their functional strengths and weaknesses and those resources that impact on vocational success. To compound the problem, students from rural communities are often plagued by isolation problems, a general unavailability of social services, massive inaccessibility, and limited educational and employment opportunities (Sarkees, 1990). As a result, it is even more beneficial for these students to become involved in the transition process as early as possible. Waiting until the student is a senior before developing appropriate work-related behaviors is too late. Under this condition, failure is often



inevitable. As a result, the importance of gaining work experience while in school—i.e., Cooperative School-to-Work Programs, the opportunity to directly experience various real life job shadows (not just read about the job), and career counseling which reconciles required job skills and abilities with the consumer realizing his/her own strengths and weaknesses—is essential. Furthermore, all individuals in transition should be required to participate in a functionally relevant job skills class. Activities should include:

- directed career exploration by rehabilitation counselors, vocational adjustment coordinators, vocational resource educators, employers and others as it relates directly to the consumer's impediment;
- job readiness training, including the development of effective field-tested individual accommodation strategies;
- participation in a support group; and
- the promotion of self-advocacy. Exercises including locus of control, appropriate goal setting, confrontation, rights, and individual learning styles are needed. An increased focus on teaching the student self-advocacy skills should be encouraged, as these skills will not develop otherwise.

Thus, for transition to occur, the educational curricula in school must relate directly to the world of work—even if that means a more functional and pragmatic curriculum—not merely to the number of hours of math or geography the school board decrees. For those students in more remote, rural areas, opportunities to directly experience real, not contrived, jobs need to be secured.

In response to the needs addressed above, a special projects and demonstration grant was secured through RSA to fund a model school-to-work rural learning disabilities project at the University of Missouri-Columbia. Through a cooperative agreement between the Missouri State Divisions of Vocational Rehabilitation and Special Education, rural students with SLD are brought to the campus, as part of the IEP, to directly experience one or several of the 7,000 jobs on campus. Those students

planning to continue their education beyond high school are placed directly in college classrooms, where their strengths and weaknesses are observed through job shadowing and situational assessment; subsequently, effective classroom accommodations can be made. Recommendations are then made to the consumer, his or her rehabilitation counselor, parents, LD teachers, and vocational adjustment coordinator as the individualization of the consumer's transition process continues.

*Expanding our efforts to identify the individual's strengths, not just weaknesses or deficits, should occur in both schools and rehabilitation settings.*

### Concluding Comments and Recommendations

President Clinton has proposed, through the passage of the Goals 2000 Educate America Act, that significant education standards be met by every child before he/she becomes an adult. As complex technological changes (as well as the human skills and abilities which drive the technology) escalate throughout our society, it is imperative that advances in both transition research and practice continue for the individual with SLD. Again, is not employment one of the goals of education?

The following are selected comments and recommendations concerning in-

dividuals with SLD as we approach the year 2000:

- Individuals with SLD can and do succeed. Just because they have a specific learning disability does not mean that they can not learn—even at very high levels. Our task, as advocates, is to find the ways they can learn and the conditions under which that learning is facilitated and to ensure that transfer or generalization of the learned skills results.

- The goal of self-advocacy must be attained. Individuals with SLD need to have control of their lives, not be subjugated to others or made to feel like second-class citizens. Consistent opportunities for successful experiences to counter the pervasive sense of failure that often develops must be made available. Non-academic tasks (e.g., clubs, jobs, volunteering, aiding) build feelings of self-worth. The practice of teaching appropriate social skills, including interpersonal communication, assertiveness, conflict resolution, network building, finding support systems, etc., needs to be required to the same extent that math class is required. Few adolescents in transition are able to accurately describe their SLD, how it impacts in school, socially, vocationally, or what specific accommodation strategies they need to experience success.

- Expanding our efforts to identify the individual's strengths, not just weaknesses or deficits, should occur in both schools and rehabilitation settings. Granted, deficits need to be determined before placement to receive special education services, or as a part of eligibility determination for VR services, but we should actively search for those skills and abilities that aid in remediation or accommodation efforts. Both the strengths and weaknesses should translate directly to functional real life behaviors.

- For the adolescent and adult with SLD, personality variables play a far greater role than previously assumed. A personal, social, and emotional assessment should be required as a part of every evaluation and staffing as the individual progresses through school to employment.



- A concerted effort should be undertaken to study those variables that predict success in persons with SLD. When possible, those variables should then be incorporated into the special education curriculum while the student is still in high school.


- The vocational rehabilitation counselor needs to get involved in school transition planning long before the future consumer is a second semester senior. This does not necessarily mean a case should officially be opened, but the counselor could act as a consultant to the school IEP team on a particular student's vocational needs. Few persons know more about the world of work for special needs individuals than rehabilitation counselors.

- Major efforts should continue in the education and training of rehabilitation counselors regarding not only the assessment of SLD, but what services you provide once eligibility is established. The rehabilitation counselor needs to serve as an advocate for the consumer by educating the employer about SLD.

- An effective recommendation for the rehabilitation counselor is to find a person who, as a previously successful SLD closure, can act as a small group leader or mentor for others with SLD as they progress through the rehabilitation process. It is a point of fact that people tend to identify with people of like need. And, the successful SLD individual can be an extremely positive advocate for another entering the world of work.

- The purview of SLD needs to be expanded both in terms of assessment as well as intervention. For example, the U.S. Department of Labor estimates that 50-80 percent of those in adult basic education programs may have a learning disability. The recently completed *National Adult Literacy Survey* determined that 80 percent of those adults self-identified with SLD had literacy skills below the required levels to be considered functionally literate (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993).

- State interagency communication and cooperation efforts—especially among special education and voca-

tional rehabilitation professionals—have to exist not just in theory, but in practice at all levels in order for effective programmatic efforts to occur at the local level. The intent should not be to “get them through school so VR can find them a job.” The job market is too competitive. To avoid underemployment, the person with SLD must be competitive as well. Therefore, effective transition programming is everyone's responsibility. To achieve these ends, a state interagency council should be created to establish policy and monitor local compliance. Representatives from the business community as well as special education and VR should be active members. 

The author wishes to extend appreciation to all who advocate for individuals with SLD as they transition to employment, with special recognition to the grant project sites, staff at the University of Missouri-Columbia, and the following individuals: Dr. Don Gann, Steve Wooderson, Dr. Rich Presberry, Merle Sindt and Bud Heineman (Missouri Division of Vocational Rehabilitation); Drs. John Allen and John Heskitt (Missouri Division of Special Education); Zanne Tillman, Jerry Abbott, Pam Martin, Yvonne Mapson, Ike Johnson, and Dr. Doug Burleigh (RSA); Dr. Dave Roberts (RCEP VII); and Colleen Fox and Jack Kite (RCEP X).

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# President Clinton Commemorates Fourth Anniversary of ADA



With President Clinton as he commemorated the fourth anniversary of the Americans with Disabilities Act at the White House on July 27 are (from left) Justin Dart, former Chair of the President's Committee on Employment of People With Disabilities; Paul Schroeder, Director of Governmental Affairs for the American Council of the Blind; Donna Shalala, Secretary of Health and Human Services; Brian Clukey, President of People First of Northern Virginia; Federico Peña, Secretary of Transportation; Deval Patrick, Assistant Attorney General for Civil Rights; Judith E. Heumann, Assistant Secretary of the Office of Special Education and Rehabilitative Services; Judy Chamberlin of the National Empowerment Center; Lee Brown, Drug Policy Coordinator; Patricia Wright, Director of Government Affairs at the Disability Rights Education and Defense Fund; Rebecca Ogle, Director of Project Accessibility: NAMES; I. King Jordan, President of Gallaudet University; and Marca Bristo, Chair of the National Council on Disability.

Addressing nearly 3,000 people July 27 on the south lawn of the White House for the fourth anniversary celebration of the signing of the Americans with Disabilities Act (ADA), President Clinton stressed the importance of ADA for all Americans.

"America cannot afford to waste the talents of a single citizen, especially

disabled citizens, the President remarked. "We are at a moment in history when our values—what we believe is morally right—and our interests—what is clearly good for us in a tangible material way—are one," he said. "We do not have a person to waste and that is why we are here today to rededicate ourselves to an America where every

man, woman, and child can reach the fullest of their God-given potential.

"Like every civil rights law in our history, the Americans with Disabilities Act is just that. It's about potential; it is not a handout. It stands for what's best in our heritage—empowering Americans to build better lives for themselves. And in that tradition, I




pledge as your President, to see that this Act is fully implemented and aggressively enforced in our schools, our workplaces, in government, and in public places for the benefit of all persons with disabilities."

The President added that "we must move from exclusion to inclusion, from dependence to independence, from paternalism to empowerment. Your future and the future of those whom you represent is at the heart of my vision for America."

Citing the appointments of 44 people with disabilities to administration positions, the President said, "We have not appointed a single, solitary person because of their disability. They have all been appointed because of their ability to serve the American people." To drive home this point, the President singled out Judith E. Heumann, Assistant Secretary of the Office of Special Education and Rehabilitative Services. "She had to fight for her first job as a teacher. She's fought for disability rights for her entire life. Now she's fighting for the future of every child in America."

President Clinton praised key participants who labored to pass ADA and those who continue to make the goals of the Act reality. Vice President Al Gore, First Lady Hillary Rodham Clinton, and Mrs. Gore, in their remarks at the commemoration, also hailed leaders of disability organizations and members of Congress for their vision of equality for all disabled Americans. Several cabinet members who worked on the passage and implementation of ADA also attended the event.

The President also stressed the importance of universal healthcare coverage to all Americans, including those with physical or mental disabilities. Underscoring universal healthcare coverage as essential for the empowerment of all Americans, he said, "The job is to rebuild the economy, to strengthen our communities, to empower our people, we cannot do that job unless you walk every step or ride every step or get there however you can. We need you and without you we cannot do it." 

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## Commissioner

*Continued from Inside cover page*

view him once they discovered he was blind. In the summer of 1978, he applied for nearly 50 different teaching positions, all to no avail. That same summer, he attended his first convention of the National Federation of the Blind, where he met the director of the Rehabilitation Agency for the Blind of Nebraska who offered him a job teaching cane travel to newly blind adults.

He worked in Nebraska for 2 years, during which time he spent summers in postgraduate training in orientation and mobility. Dr. Schroeder was the first blind person in the nation to be admitted to a university program in orientation and mobility. In spite of successfully completing the program and earning the respect of the faculty, he was denied certification on the basis of blindness. The professional organization which certifies orientation and mobility specialists held fast to the belief that it was unsafe for a blind person to train other blind people to travel with a cane, even though Dr. Schroeder had completed all of the required courses and had already been teaching successfully for 2 years.

In the fall of 1980, he returned to Albuquerque to begin employment with the Albuquerque Public Schools as an itinerant teacher of blind children. One year later, at the age of 24, he was promoted to supervise 57 staff in the low incidence program, which included districtwide services for blind and deaf children. He served in this capacity until June 1986. During this period, he established the first program in the nation to introduce cane travel training to young elementary school-aged blind children.

At that time, he became acutely aware of the problems faced by blind people in trying to secure adequate rehabilitation training.

In 1985, he enlisted the aid of Manny Aragon, a prominent state senator, to introduce a bill that would reorganize the state's services for the blind. Although the bill died in the waning hours of the legislative session, Dr. Schroeder was undaunted. The next year, with broad based legislative support and dozens

of hours of testimony by blind persons throughout the state, the bill was reintroduced and passed into law. On July 1, 1986, at the age of 29, he became the first director of the newly created New Mexico Commission for the Blind. Prior to the Commission's establishment, blind sheltered workshop workers in New Mexico received sub-minimum wages, resulting in some workers receiving paychecks of less than \$5 for 2 weeks of work. Today, sheltered workshop workers in New Mexico are guaranteed the minimum wage and a full benefits package, including health insurance and a retirement program. The Commission's Orientation Center now provides the training which blind people need to re-enter the work force and live independent productive lives. The Commission's Business Enterprise Program has increased earnings among blind food service managers by more than 20 percent, making their earnings comparable to the per capita income of the state's citizens at-large.

Dr. Schroeder's commitment to improved services for blind people goes far beyond simply improving existing programs. In August 1990, the Commission introduced a state-of-the-art information service known as *Newsline for the Blind*, which gives blind persons immediate access to the daily newspaper. Through a combination of specially modified computer equipment and a small army of dedicated volunteers, the entire newspaper is recorded each morning for use by blind people in New Mexico. The blind person using the service needs only to have a touch-tone telephone.


Both in his professional and volunteer activities, Dr. Schroeder contributes his time and energy to improving the quality of life for blind people and people with other disabilities. He served as the youngest member of the board of directors of the National Federation of the Blind from 1984 to 1994. Until his appointment as RSA commissioner, he served as president-elect of the National Council of State Agencies for the Blind and as the first president of the International Council on English Braille which he helped to found in 1991. He was a member of the board of the



Braille Authority of North America and has served on the governing board of the New Mexico Registry of Interpreters for the Deaf. Additionally, he was a member of New Mexico's Developmental Disabilities Planning Council and the Governors Committee on Concerns of the Handicapped. Until his current assignment his most recent appointment was to the Civil Rights Reviewing Authority of the U.S. Department of Education. While he contributes his time to a wide range of activities, he will be the first to tell you that through community service his own life has been enriched. "As a young person losing my sight, I was fortunate to have many people in my life to assist me in obtaining training and the confidence I needed to become a productive member of society. The rehabilitation system is the primary means by which people with disabilities can gain the skills needed for social and economic integration. President Clinton believes in America and in its people and this includes people with disabilities. Our job is to make sure that the rehabilitation system is responsive and effective in helping people with disabilities secure challenging and rewarding employment."

Until his appointment as RSA commissioner, Dr. Schroeder served as executive director of the New Mexico Commission for the Blind. In this capacity, he was responsible for a variety of statewide services targeted at correcting the 70 percent unemployment rate experienced by blind people nationwide. As the director of a state agency, he had to function as an advocate for the needs of blind people in his state and articulate those needs to the state legislature and to the public in ways which would result in achieving necessary funding and community support.

In the midst of his many other achievements, he was able to earn a Ph.D. degree in educational administration from the University of New Mexico in May 1994.

He married his wife, Cathlene, in 1981. They have two children: Carrie, 12, and Matthew, 10. 

## NEW PUBLICATIONS AND FILMS

### **Model Program Operation Manual for Business Enterprise Program Supervisors.**

*J. Elton Moore and Angula Tucker. Mississippi State University, Rehabilitation Research and Training Center on Blindness and Low Vision, P.O. Drawer 6189, Mississippi State, MS 39762. 199 pages. Softcover, \$20; Braille copies, \$60. Also available on audiocassette and floppy diskette upon request.*

Designed as a model and/or resource for rehabilitation agencies and Business Enterprise Program personnel to consider in improving their own Randolph-Sheppard programs, this manual provides comprehensive and in-depth information on the Randolph-Sheppard Act and the Business Enterprise Program, including the legal background of the act, a detailed history of both the act and the program, requirements and procedures for establishing new vending facilities, licensing requirements, and much more. It should prove itself to be a valuable resource for vocational rehabilitation professionals and anyone involved with services and programs for blind and visually impaired people.

### **A Woman's Guide to Coping with Disability.**

*Resources for Rehabilitation, 33 Bedford Street, Suite 19A, Lexington, MA 02173. \$39.50 plus \$5 shipping and handling.*

This publication addresses the special needs of women with disabilities and chronic conditions, such as social relationships, sexual functioning, pregnancy, childrearing, caregiving, and employment. Special attention is paid to ways in which women can advocate for their rights with the health-care and rehabilitation systems. Written for women of all ages, the book has chapters on the disabilities that are most prevalent in women or likely to affect the roles and physical functions

unique to women. Included are arthritis, diabetes, epilepsy, lupus, multiple sclerosis, osteoporosis, and spinal cord injury. Each chapter features information about the condition, service providers, and psychological aspects, as well as descriptions of organizations, publications and tapes, and special assistive devices.

For a complete list of publications, contact Resources for Rehabilitation, 33 Bedford Street, Suite 19A, Lexington, MA 02173. Telephone (617) 862-6455; FAX (617) 861-7517. Resources for Rehabilitation is a nonprofit organization that provides training and information to the public and to professionals who serve individuals with disabilities.

### **Medical Aspects of Disability.**

#### **A Handbook for the Rehabilitation Professional.**

*Myron G. Eisenberg, Robert L. Glueckauf, and Herbert H. Zaretsky, editors. Springer Publishing Company, 536 Broadway, New York, NY 10012. 414 pages. Hardcover, \$48.95.*

This handbook was produced in response to the need for a text that provides concise, current, yet comprehensive and authoritative, coverage of medical aspects of disabling conditions, including discussions of their functional presentation, prognosis, psychological and vocational sequelae, and other background information critical to the study of disability.

This is a text designed to assist the student preparing for a career in the field of rehabilitation and the practitioner in need of a reference guide. However, comprehensiveness of coverage in a single volume on a topic of this dimension has realistic limits. Therefore, readers looking for exhaustive coverage of specific conditions can turn to other sources, many of which are identified in this text's extensive reference lists.



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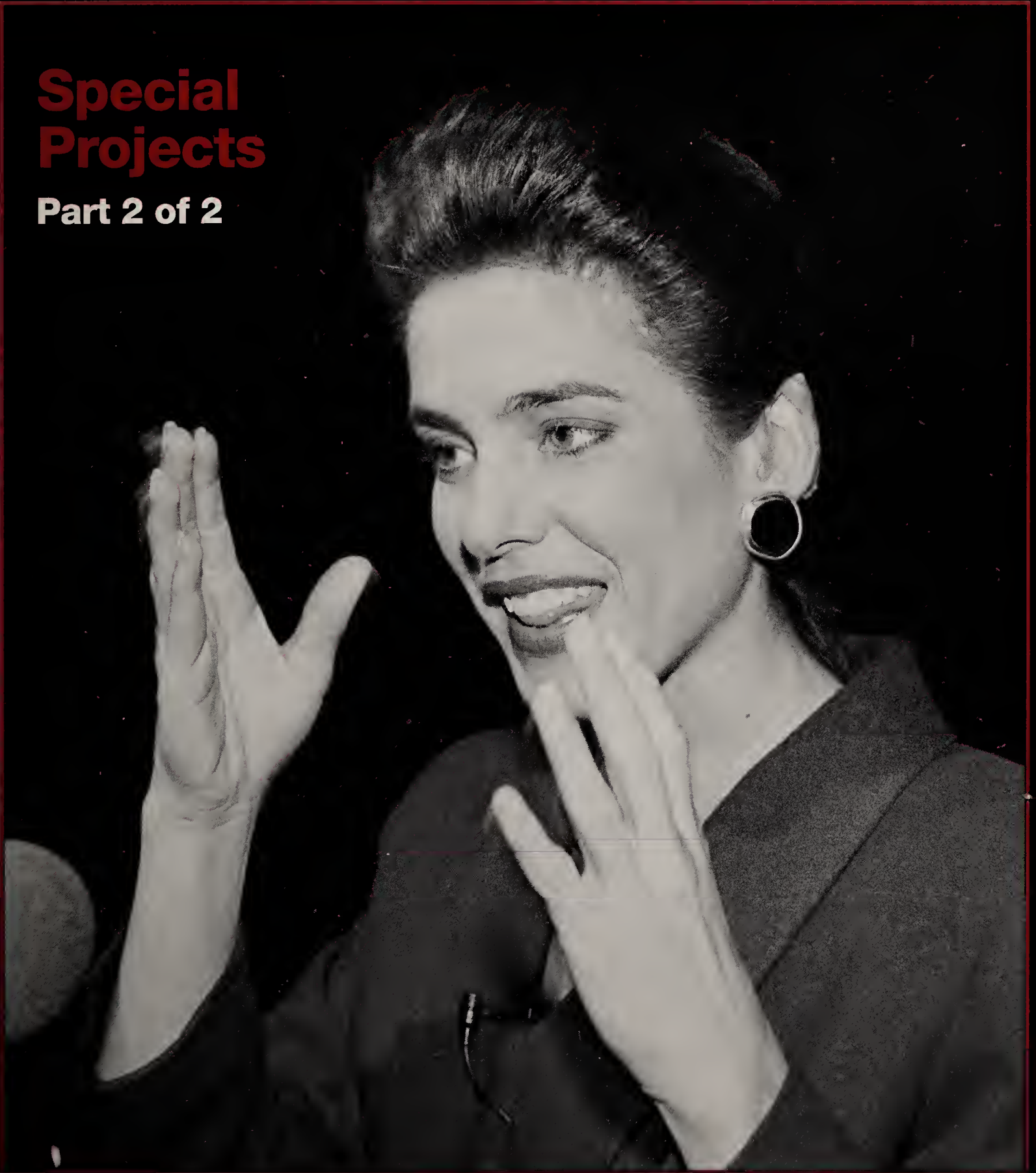
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# AMERICAN Autumn 1994 REHABILITATION

## Special Projects

Part 2 of 2





# Anything is Possible

**M**any young people in America today are challenged. Some face unthinkable adversities and, despite the odds, enjoy healthy and productive lives. Yet those who are unable to overcome their obstacles and find a path of productivity often suffer, in part, from an overwhelming lack of self-esteem and the absence of positive environments in which they are challenged to try, fail, try again, and, ultimately, succeed.

In facing my own life's challenges, I have discovered a unique approach that I call **STARS: SUCCESS THROUGH ACTION AND REALIZATION (OF YOUR DREAMS)**. The five points of a star itself have continually reminded me that the essential elements to achieving success are: *To have a positive attitude; To believe in your dream, especially education, which is a dream all Americans share; To face your obstacles, no matter how great; To work hard; and To build a support team.*

As I travel this country in my role as Miss America, I will communicate the STARS approach to our nation's youth. I will teach them, through word and deed, the value of setting high goals, working hard and achieving their dreams and ambitions, reminding them that their actions speak louder than any words. I will also carry this message to parents, teachers, counselors, ministers, and others who influence youth, imploring them to create the proper environments for young people to employ STARS and to serve as committed members of a young person's support team.

As a living example of a challenged person who has used a STARS approach to succeed, I will extend my hand to anyone in need of encouragement and love. I will ask them not to imitate me, but rather to believe in themselves and the power of their spirit. And I will reach out to specific



**Heather Whitestone**  
Miss America 1995

Photo by Andrew Eccles/Edge

groups with whom I share a special bond.

I will motivate all young people who are deaf or hard of hearing to pursue a broad range of communication and educational options in their lives, choosing those which best reflect their goals and encouraging them to choose the options that will build their self-esteem and, ultimately, ensure their success in life.

I will invite youth with disabilities to join me in reaching out to the nondisabled world—without fear or concern—to tear down the barriers of acceptance that still exist

by demonstrating that their lives are about their *abilities*, not their *disabilities*. In doing so, I know they will find their own paths to success.

I will encourage all young people facing challenges to confront their obstacles with determination and confidence, avoiding the epidemic of negative thinking that has swept our country and robbed them of their self-esteem. I will help them to realize their own success by setting very clear goals and working hard to achieve them.

And I will challenge opinion leaders and those who influence youth to work ever harder at creating the proper environments for all young people—disabled and nondisabled—to confidently establish their own identity, helping them to find a productive place in our society, and inspiring them always to try, try again, and one day, to *succeed*.

To these young people and countless others, I will commit myself, speaking out on their behalf when they cannot. I will believe in their dreams. I will help them to work hard. And I will always be the very first member of their support team.

These promises I make today, the fifth day of October, 1994.

# AMERICAN REHABILITATION

Volume 20, Number 3

Autumn 1994

The weakest ink is better than the strongest memory.

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## DEPARTMENTS

### 45 New Publications and Films

Cover Photo: Heather Whitestone, who is profoundly deaf and the first woman with a disability to be chosen Miss America, addresses deaf students with her message of "Anything is Possible" (see Cover 2, opposite) at Gallaudet University, Washington, DC.

U.S. DEPARTMENT OF EDUCATION  
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Manuscript and article suggestions are welcome. Write to: Editor, *American Rehabilitation*, Rehabilitation Services Administration, Room 3212, 330 C Street SW, Washington, DC 20202-2531. Telephone: (202) 205-8296. FAX: (202) 205-9874.

Paid subscriptions are accepted (\$9.00 domestic, \$11.25 foreign; single copies are \$3.75 domestic and \$4.69 foreign). See back cover for order blank. Correspondence concerning paid subscriptions should be sent to Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402. POSTMASTER: Send address changes to *American Rehabilitation*, 330 C Street SW, Washington, DC 20202-2531.



# The Role of the Job Coach: Orchestrating Community and Workplace Supports

***Supported employment is one of rehabilitation's most valuable tools for assisting people with severe disabilities in becoming successfully employed at competitive jobs in the community. The evolution of the model has resulted in new and innovative support technologies which offer consumers of supported employment greater opportunities for directing their careers and choosing the type and amount of assistance they would like to receive. This article describes a model of supported employment service delivery<sup>1</sup> that enhances the role of the job coach in maximizing the use of employer, coworker, community, and family supports to enable an individual to obtain, learn, and maintain a job of his or her own choosing.***

*Wendy Parent, Ph.D.  
Darlene Unger, M.Ed.  
Karen Gibson, B.S.  
Carlyle Clements, M.S.*

**T**housands of individuals with severe disabilities who were unable to work successfully within the traditional vocational rehabilitation model have had improved employment outcomes through supported employment, which is characterized by individualized support on and off the job-site, initial and ongoing employment services, and assistance from a skilled job coach. Supported employment has become widely recognized as the most effective approach for achieving meaningful employment for individuals with a variety of disability labels (Bellamy, Rhodes, Mank, & Albin, 1988; Rusch, 1990; Wehman, Sale, & Parent, 1992). It has provided the mechanism which has allowed many people to enter the competitive labor force for the first time and experience the outcomes of work that are well-known to the general population. Individuals who are working with assistance from supported employment are reported to be earning increased wages (Revell, Wehman, Kregel, West, & Rayfield, 1994; Wehman, 1992), maintaining regular hours (Rehabilitation Services Administration, 1993), receiving company benefits (West, Kregel, & Banks, 1990), performing a wide variety of jobs (Rehabilitation Services Administration, 1993; State of New York, 1993), and experiencing some degree of integration at their jobsites (Chadsey-Rusch, Gonzales, & Tines, 1988; Parent, Kregel, Metzler, & Twardzik, 1992; Parent & Wehman, 1994). Perhaps most importantly, individuals working in supported employment tend to be highly

satisfied and report that they like their jobs, the services they have received, and the type and amount of assistance provided by their job coaches (Parent, 1994; Test, Hinson, Solow, & Keul, 1993).

The success of supported employment can be directly attributed to two important and unique features which distinguish this approach from other vocational options.

One is the provision of individualized supports to assist persons with severe disabilities in becoming equal participants in the competitive labor force. This support is generally aimed at:

- identifying individuals' skills and interests (*consumer assessment*),
- finding them a job (*job development*),
- making the necessary startup arrangements (*job placement*),
- teaching them how to do the job (*jobsite training*), and
- providing needed assistance for as long as the worker is employed (*on-going follow-along services*) (Moon, Goodall, Barcus, & Brooke, 1986; Wehman & Kregel, 1985). While these five components of the supported employment model remain the same, the level and intensity of support for each person is likely to vary, depending upon the individual and his/her specific situation.

Second is the role of a job coach or employment specialist who functions as trainer, advocate, and facilitator in providing and coordinating the above supports (Wehman & Melia, 1985; Sale, Wood, Barcus, & Moon, 1988). The responsibilities of the job coach are varied, with primary emphasis on insuring the delivery of whatever work and work-related assistance individuals need to become employed and maintain their jobs. This includes addressing issues on and away from the jobsite,



such as transportation, case management, Social Security, interpersonal relationships, skill training, grooming, lunch and breaks, supervision, and career advancement. The individualized nature of the model in the delivery of needed supports in conjunction with the services of a professional job coach have been the major reasons why supported employment has been so widely accepted and promoted by consumers (Brooke, Barcus, & Inge, 1992; Parent, 1994), parents (Beckett & Fluke, 1988; Moore, 1988), employers (Shafer, Hill, Seyfarth, & Wehman, 1987; Kregel & Unger, 1993), and job coaches (APSE, 5001 West Broad Street, Suite 34, Richmond, VA 23230; Everson, 1991).

Despite the tremendous number of people who were unemployed and are now working with the help of supported employment, thousands more continue to sit at home, attend day activity programs, or are enrolled in sheltered workshops. Recent efforts have focused upon developing additional support technologies aimed at enhancing service delivery practices to better meet the needs of all individuals interested in community-based employment. Identifying new and effective approaches for better supporting workers with severe disabilities and assisting greater numbers of people who would like to enter the work force is a critical element in the continued growth and expansion of supported employment services (Kregel & Wehman, 1989). Innovations, such as assistive technology, rehabilitation engineering, compensatory strategies, natural supports, job modifications, job carving, and personal assistant services have opened the door to employment for many people previously considered too severely disabled to work (Hagner & Dileo, 1993; Mank, in press; Nisbet, 1992; Wehman, Sale, & Parent, 1992). As a result, job coaches now have a much more extensive array of tools, in addition to behavioral training techniques, with which to support workers with severe disabilities in competitive jobs in the community.

Unfortunately, advancements in technology do not always translate into practice at the direct service level as evidenced by inconsistencies in sup-



*Worker receives on-the-job training from a coworker.*

ported employment implementation nationwide (Wehman & Kregel, 1994; Murphy, Rogan, & Fisher, 1994). The use of new innovations and support strategies are all too often based on the philosophy of the programs, the knowledge of the providers, or the skills of the job coaches, rather than the needs and preferences of consumers (Brooke, Barcus, & Inge, 1992). Decisions about specific supports are frequently dictated by an individual's disability label—rehabilitation engineering, assistive technology, or personal assistant services for persons with physical disabilities; compensatory strategies for persons with traumatic brain injury; job modi-

fications or job carving for persons with mental retardation or mental illness; and natural supports for persons with mild to moderate disabilities. In actuality, *anyone* participating in supported employment could potentially benefit

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from *any* support technology and should have access to whatever type of assistance he or she chooses to receive at the time that he or she would like to use it. This can include natural and human service supports provided by the workplace, community, family, friends, or job coaches, depending upon the choice of the individual participant. The bottom line in the delivery of supported employment services is the provision of any and all supports selected by the consumer in a manner of his/her own choosing with whatever degree of assistance he or she prefers.

As supported employment evolves to incorporate consumer choice initiatives and a variety of new support technologies, the role of the job coach becomes even more critical as greater responsibilities and expectations are demanded. In addition to being adept in traditional supported employment service methodologies, job coaches must also have the knowledge and skills to develop business and community support resources, facilitate informed choices, assist with accessing preferred supports, provide a variety of individualized supports, coordinate and monitor all types of assistance, and respond to any changes over time. The major difference between the model of the nineties and traditional supported employment is the way problems and issues are perceived and addressed by the job coach. Rather than responding to a support need by first providing the assistance themselves, job coaches should assess the situation with the consumer, share information about all possible support options, assist the individual with accessing the support of his/her choice, and provide ongoing assistance with whatever help is desired.

## Developing Support Resources

The first step in utilizing an array of support options is finding out what type of assistance is potentially available in the community and different employment settings. This can only be accomplished by becoming familiar with the local community and the many support resources available to

**Table 1.**  
**Examples of Support Option Resources**

### Employer Supports

Coworker Mentor  
Company Videotape Training  
Coworker Training or Monitoring  
Company Sponsored Computer/Electronic Accommodation Program  
Employee Assistance Program  
Restructuring Job Duties  
Scheduling Flexibility  
Supervisor Prompting or Monitoring  
Job Duty Checklist Provided by Employer  
Supervisor and Coworker Advocacy  
Employer Counseling

### Transportation Supports

Taxi  
Riding with a Coworker  
Walking  
Riding a Bicycle  
Driven by Parents  
Bus

### Community Supports

Cooperative Extension Service (e.g., Financial Management)  
Independent Living Center  
College Students from Education, Rehabilitation Counseling, & Business Departments (e.g., peer mentors, tutors)  
State Assistive Technology Systems  
Planned Parenthood Courses  
Red Cross Safety Courses  
YWCA Safety Prevention Courses  
Social Security Work Incentive Specialist/Consultant  
Auto Club Driving School  
Virginia Employment Commission  
Community Sponsored Childcare Courses  
Neighbors

### Personal and Independent Living Supports

Changed Locks and Made Keys for Personal Security  
Budgeting and Financial Management Assistance  
Purchased an Alarm Clock  
Counseling (e.g., rehabilitation counselor, case manager, private counselor)  
Purchased a Digital Watch  
Purchased a Raincoat and Boots  
Purchased a Reflective Vest and Flashlight  
Identified Advocate Assisting with Housing  
Community Residential Facility Personnel and Housemates Assisting with Getting Up and Ready for Work

### Recreation and Social Integration Supports

Volunteer with Rescue Squad  
Jaycees  
YMCA  
Neighborhood Community Association  
Attending After Work Social Activities with Coworkers  
Parks and Recreation Programs  
Company Sponsored Recreation Activities (e.g., bowling, going to an amusement park)  
Linking Up with a Friend to go Skating, Bowling, and Out to Lunch

and used by individuals with and without disability. Similar to the community job market analysis typically conducted by most supported employment programs, identifying community and workplace support options requires that personal contact be made with various agencies, organizations, associations, and businesses (Moon, Goodall, Barcus, & Brooke, 1986; Parent, Sherron, Stallard, & Booth, 1993).

Organizations or agencies to investigate can be identified from a variety of sources. Those found to be the most productive include those contacted through personal friends, acquaintances, or experiences; the telephone book; the consumer and his/her friends; the newspaper; and other colleagues. Five general types of support option categories have been identified. These include:

- employer supports,
- transportation supports,
- community supports,
- personal and independent living supports, and
- recreation and social integration supports.

Several examples of different kinds of support options identified within each of these categories are listed in Table 1. The information can be compiled in a loose leaf notebook that serves as a resource guide at the time that specific support needs are identified.

## Choosing and Accessing Community and Workplace Supports

Taking full advantage of all the support resources available to assist an individual to achieve his/her employment goals does not typically happen for persons with severe disabilities. Just because a support is available at the workplace or in the community does not necessarily mean that the consumer will automatically access it or benefit from its use. It is not uncommon for an individual to not know that potential supports are available, how to choose among the alternatives, or how to go about accessing a desired support. A critical factor in the use of a variety of supports is the role of the job coach

<b>Table 2.</b> <b>A Systematic Process for Utilizing Community and Workplace Supports</b>	
1.	Determine individual needs and preferences
2.	Brainstorm potential options
3.	Assess job and community supports
4.	Identify individual choices
5.	Develop strategies for accessing supports
6.	Evaluate support effectiveness
7.	Arrange provisions for ongoing monitoring

who helps the consumer with identifying, choosing, and accessing needed supports at whatever level of assistance he or she prefers. A systematic process for utilizing community and workplace supports in supported employment includes the components shown in Table 2, which highlights these steps to be followed for any support need identified during all phases of the supported employment model.

Each of the steps in this process is briefly described below.

*It is important to identify the types of assistance that a consumer needs or would like to receive in order to gain and maintain employment.*

## Determine Individual Needs and Preferences

It is important to identify the types of assistance that a consumer needs or would like to receive in order to gain and maintain employment. These can be related to finding a job, learning how to do the job, maintaining work performance, developing social relationships, or other work and nonwork related issues both on and off the job-

site. For example, an individual may be concerned over not having transportation to and from work, being shy and having difficulty making friends, not being able to perform the job as fast as coworkers doing the same task, or not knowing how to cash a paycheck and count money.

The best strategy for determining an individual's job and support preferences is to ask him/her. Meeting with the individual and, if possible, with significant others provides an excellent opportunity to introduce yourself, explain the types of services offered by your program, "break the ice" and get acquainted, begin identifying their interests, and arrange times to meet again. For example, one individual indicated that he could not handle working full-time hours, another stated that she preferred a job with physical activity to help keep her weight down, another person said that he had trouble remembering things and would need assistance to prevent him from forgetting, and another reported that she had difficulty getting up in the morning and needed help preparing for work. Multiple visits either by telephone or in person are helpful in establishing rapport and a trusting working relationship so critical to supporting successful employment. Ongoing communication is essential to determine if an individual's support needs or preferences have changed so that new or additional supports can be arranged.

Two useful techniques proven to be extremely valuable in determining individual preferences are community



and situational assessments. With a community assessment, one or two job coaches get together with the individual and take him/her out riding in the car for several hours. The individual is asked to guide the job coach around his/or her neighborhood and point out favorite places, where friends and neighbors live, areas typically frequented by the individual or his/or her family, and places that he or she might be interested in learning more about. This provides an excellent opportunity to become familiar with the local area where the individual lives, to identify potential support resources, and to determine job preferences. One person pointed out the residence of his friend who worked at a grocery store just "like I would like to do"; another showed the job coach where her grandfather lived whom she said could drive her to and from work everyday; another individual asked to go by the mall since her dream was to be a model and she liked to go there; and another asked to visit a particular electronics/music store, because he loved music and always wanted to see what kind of jobs might be available. A situational assessment allows an individual to try out a real job at a community business for a 4-hour period (Moon, Inge, Wehman, Brooke, & Barcus, 1990). Typically, several assessment sites are arranged which reflect a wide variety of jobs frequently available in the locality. For example, housekeeping and laundry at a hotel, dishwashing at a restaurant, clerical at a business office, bagging at a grocery store, and locker attendant at a fitness center. Individuals are asked to pick two or three of the jobs that they would like to try. Actually going out into the community provides opportunities to show the job coach firsthand what the person likes even when previously asked questions concerning likes and dislikes may have resulted in minimal response.

### **Brainstorm Potential Options**

For every support need that is identified, a variety of support resources

that could be available should be selected. This is a good time not only to return to the "cook book" of support options investigated during the community analysis, but to explore any other ideas that come to mind. However, caution should be used to prevent being limited to only considering these supports and not pursuing other new ideas that may be more specifically related to the person or situation. Perhaps the individual's church, neighbors, or the Moose Club which a family member belongs to may be available to assist in a multitude of ways.

For example, a person with an expressed need to receive money management was provided with the following resources from which to choose: a business school student to tutor, a volunteer through the Cooperative Extension Service, a course offered by a community college, and a friend to lend a hand. Similarly, an individual in need of transportation may consider the following options: carpooling with coworkers, walking, taking a taxi, or riding with parents. It is important at this time to think about everything that might be available, no matter how remote the possibility or unlikely the support resource might be. Decisions based upon what is actually available and what the individual would like to use are made at a later date from the extensive list of options identified during this brainstorming period.

### **Assess Job and Community Supports**

All of the ideas generated should be discussed with the consumer, including a clear and detailed explanation of just what utilizing a support of this nature would entail. The availability of the support option, the pros and cons of each, and the level of interest expressed by the individual can be explored at this time. Assessing these factors can provide some direction for pursuing supported employment activities. For example, an individual in need of transportation who generally can choose between the bus, a taxi, carpooling with coworkers, or riding a bicycle, but re-

fuses to ride the bus, does not have taxi service, and can only ride a bicycle within a 2-mile radius of home would require specific job development emphasizing a close location or other coworkers to ride with.

Additionally, one job may offer new employee orientation training, another job may provide coworker mentoring, another may informally support employees on an individualized basis as needed, and another may expect employees to fend for themselves with minimal help from the company. The varying levels of support offered by these employment settings combined with other characteristics of the job, such as hours, wages, coworkers, and location, are likely to greatly influence an individual's decision about which company to choose. Similarly, the assistance available to someone who has difficulty getting up and preparing for work may include morning routine and alarm clock training, a paid tutor, personal assistant services, negotiating afternoon or evening hours with the employer, or assistance from family or residential staff. Describing how these supports could be used, what they have to offer, and the type of assistance that could be received allows the individual to select the job and support resources that best meet his or her needs.

### **Identify Individual Choices**

Individuals may have difficulty selecting the most desirable job and appropriate supports without sufficient information presented in a manner they can understand. Some individuals may not know what the different options are, others may not know their preferences, and others may lack the skills to make a choice among the alternatives. The job coach can help by providing concrete information—either verbally, in written form, and/or through direct experience, e.g., having the individual accompany the job coach when making employer contacts, a strategy which allows the individual to look directly at the job and assess its desirability; it also provides the op-



portunity to make that critical first impression with the employer.

In some cases, the individual may prefer to talk with or visit the person or organization so that he or she can decide whether this is the "best support for me." Also, trying out the support before committing to its use allows an individual to determine firsthand if he or she is interested. For example, an individual with a need for transportation assistance interviewed coworkers who volunteered to car pool, tried walking, talked to a relative who was not working, and practiced using a taxi to decide what resources might best work for her. She decided that she enjoyed riding with her aunt or coworkers. In descending order of preference, she favored walking, taking a taxi, and riding with one coworker whom she liked. A transportation plan was developed for her which included the options in her order of priority, along with telephone numbers, availability, and costs, to be hung on the wall next to her telephone. It is not uncommon for an individual to choose a combination of supports or to change a single support option over the course of time as needs, preferences, or availability fluctuate.

## Develop Strategies for Accessing Supports

Simply because a community or workplace support is available does not necessarily ensure that a person interested in using it will automatically have access to it. Our experience suggests that a more formalized process for accessing supports must be initiated. This typically involves assisting the individual with contacting the support resource and making the specific arrangements for its use. Often, accessing supports requires giving the individual specific steps to follow, guiding him/her through the process, and accompanying him/her during the initial meeting or use of the support. For example, asking the individual to pick up job applications or to contact any interesting employers about a job opening may not be as productive as asking



*Job duties are completed with the support of an employer-provided checklist.*

that person to come to your office, deciding on specific employers to call, and providing a telephone to actually make the calls. Similarly, an individual employed by a company that offers a coworker mentor may need help in linking up with that coworker, expressing his/her support needs, learning how to communicate with the coworker, and indicating his/her preferences if a more compatible coworker is desired.

Frequently, a valuable support option for maintaining employment does not require another person to provide it, but another person's assistance would likely be needed to obtain it. For example, one individual with a desire to keep his possessions in strict order became employed as a grocery bagger. Because he did not like getting wet while taking groceries to cars in the rain, and to prevent upsetting the order of his clothes by wearing his raincoat, the job coach accompanied him to a department store to buy a raincoat, umbrella, and lock. Additionally, a request was made to the employer for a locker to store his possessions in a specific order, untouched by anyone, so they would be available whenever he needed them.

Similarly, "Debbie," who was employed as a teacher's aide at a daycare center needed assistance in caring for the 1-year-old children from 5 to 5:30 p.m., after the teacher left for the day. After brainstorming the options with her job coach and her mother, Debbie first chose another teacher—who worked in the same room but on the other side of the partition—to assist her. However, because there were so many children and the teacher's availability was unpredictable, she continued to have difficulties in caring for the children and required ongoing intervention by the job coach to ensure proper supervision. Interested in pursuing other options, she went shopping with the job coach, bought children's toys, and placed them in a decorated box labeled "Debbie's Box." The toy box was kept in the closet until 5 p.m. and removed for the last 30 minutes of the day. The children were so excited about going through the box and pulling out the new toys that they would ask for it each day and then quietly play in a group until 5:30. Debbie was able to take care of the children without the job coach's assistance and the parents praised her for doing such a good job. The employer



found this to work so well that she was interested in implementing the same idea in all of the classrooms.

***Once a support has been arranged, its effectiveness towards meeting the individual's needs must be determined.***

### Evaluate Support Effectiveness

Once a support has been arranged, its effectiveness towards meeting the individual's needs must be determined. *The receipt of assistance alone is not an assurance that the intended outcome has been achieved.* Rather, it is important that multiple measures of the quality, stability, and desirability of the support be obtained from all persons potentially affected, such as the consumer, employer, coworkers, family, and members of the community. For example, one company indicated at the time of hiring that typical practices were to pair a senior coworker mentor with a new employee until he/she was able to perform the job. On the first day, circumstances developed that required the assigned mentor to be pulled away after only 15 minutes. The new worker then requested assistance from the job coach, who was available to help the mentor or worker as needed. Discussions with the employer revealed that he did not realize how important it was for the new worker to receive constant training for an extended period of time; the employer agreed to schedule the worker during slower shifts to insure

that a coworker could be available the entire time.

Another individual, who was employed as a computer operator, required assistive technology and jobsite modifications. The supervisor and the company's computer/electronic accommodation program worked with the individual to identify the types of supports that would assist him to perform the job. The computer was modified to process more slowly, a computer was made available for practice at home, pertinent information was highlighted and posted around the work station, a mentor was assigned to teach the job duties, and extended probationary and training time was arranged. When continued slow work and high error rates placed the individual's job in jeopardy, the worker requested help from the job coach, who then helped with systematizing the job routine, modifying the way documents were processed, obtaining a device for holding work at eye level, installing an auto-repeat key, setting up a three-step proofing guide, and working with the employer to determine the best supervisory and reinforcement strategies. The employer then took the lead in implementing and monitoring the various support options necessary to achieve the quality and production rates required of the position.

In determining the effectiveness of a support, a variety of factors need to be considered: Is the consumer satisfied with the arrangement? Are the individual's needs being met? How is the support impacting on employment (e.g., wages, hours, quality, speed)? Is integration enhanced as a result of the support? Is the employer satisfied? Are the company's standards being maintained? Any support is only as good as the results it produces. The best support may be useless if the consumer is not happy or if no benefits to the individual and/or workplace are realized. Flexibility, creativity, and resourcefulness are essential elements that contribute to a combination of community, workplace, and job coach supports that meet the individualized needs of consumers.

### Arrange Provisions for Ongoing Monitoring

The stability and dependability of community and workplace supports are critical to employment success. Regardless of what supports are in place throughout the individual's employment tenure, provisions for *ongoing* monitoring must be made to proactively ensure that the necessary support is maintained. A multitude of factors can influence the reliability of an ongoing support, such as:

- a change in the needs and preferences of the individual,
- coworker and supervisor turnover on the jobsite,
- a modification in work procedures or job duty responsibilities,
- a geographical change in the individual's living situation, or
- a desire by a community volunteer to terminate the previously arranged helping relationship.

For example, an individual who had previously been employed at a variety of jobs only to lose them due to difficulties in getting ready for work every day chose a job as a busperson at his favorite restaurant, which offered the hours, location, job duties, and coworkers he was interested in. He asked the job coach to help him solve his problem of getting up and ready for work on time. He and the job coach brainstormed many different options; after trying them all, the individual selected the following, in order of priority:

- paying a peer to help,
- arranging a student volunteer, and
- hiring a paid attendant.

A list of each person's name, telephone number, and hours of availability was developed and arrangements were made for a friend to contact them.

By overseeing the support and employment situation, through regular visits to the jobsite, ongoing communication with the individual and employer, periodic assessments of consumer and supervisor satisfaction, and systematic data collection aimed at monitoring work performance, the job coach can be the stable point of contact should a change or breakdown in the support



occur. One individual's follow-along support was provided by his supervisor and his mother who communicated weekly regarding his performance. The worker and his mother contacted the job coach twice a month to relay information regarding his work and the availability of the supports provided by his employer. Infrequent and random visits were made by the job coach to monitor the situation and address problems as they occurred, such as advocating for more hours, facilitating coworker training on a new job task, and assisting with arranging new transportation upon the consumer's request. The most important features of any systematic ongoing support plan are:

- clear delineation of responsibilities,
- regular monitoring, and
- a stable contact person who can temporarily provide services in the event that the community and workplace supports are no longer effective.

Often, putting pertinent information in writing, such as monitoring activities, frequency of ongoing assistance, the roles of key people, and the name and contact information for the job coach, helps to alleviate uncertainties and prevent any upcoming need for assistance going undetected.

## Discussion

The use of community and workplace supports for supported employment represents the state-of-the-art in assisting people with severe disabilities in the competitive jobs of their choice. Building upon the knowledge and successes of the last decade, the development and utilization of a variety of innovative support technologies further enhances service delivery practices to better meet the needs of all people who would like to work and receive assistance from supported employment. The evolution of the model into a consumer-driven approach, with opportunities for choice from an endless variety of creative support options, is the next logical step in the continuous effort to improve an already established and successful service modality. However, as the field of

supported employment moves to this next level, several critical points must be acknowledged.

*The utilization of community and workplace supports is not a panacea for correcting all of the shortcomings observed in supported employment implementation.* It will not fix all of the inconsistencies in service delivery, the lack of funding resources, the shortages of skilled job coaches, the disincentives for conversion, the interagency turf issues, the large numbers of persons on waiting lists for services, or the poor quality outcomes reported for some supported employment participants (e.g., low wages, minimal integration, few hours, lack of career advancement). What it will do is place consumers in the driver's seat, allow them to direct their careers, and truly choose the type and amount of assistance they would like to receive to be successful.

***People with disabilities want to work in real jobs and supported employment offers the means for achieving this goal.***

*The basic premises on which supported employment was established have not changed despite the expansion to include new service technologies.* People with disabilities want to work in real jobs and supported employment offers the means for achieving this goal. No support strategy or methodology, regardless of how

good it sounds, should compromise the values on which this vocational model was based. Individuals have the right to be employed by community businesses where they earn comparable wages, work side-by-side with their coworkers, receive worthwhile hours, and experience all of the same benefits as other employees of the company. Most importantly, they should be able to choose these characteristics of their jobs and change their minds as their needs and preferences dictate.

*The reliance on community and workplace supports is not an all- or-nothing approach, but rather one of the supportive features of the existing supported employment model.* The job coach is responsible for implementing all of the services characteristic of the consumer assessment, job development, job placement, jobsite training, and ongoing follow-along phases of supported employment. However, each consumer needs different types of assistance and the same individual will need varying levels of support at different times in the employment process. The type of support a worker receives to meet each of these needs and how it is provided is decided by that person using the systematic process outlined in this article. An individual with extensive jobsite training needs, for example, may choose to have a coworker teach one task, the job coach teach another, parents arrange transportation, the rehabilitation counselor purchase uniforms, a friend assist with managing his/her paycheck, the cafeteria personnel help with lunch and other breaks, the job coach accompany him/her for social events on the job and after work hours, the supervisor monitor work performance, and a Social Security consultant assist with writing a PASS Plan.<sup>2</sup>

*With the advent of new and creative support technologies, the job coach's role is not eliminated but instead remains, more than ever, an essential element of the model.* It is evident that community and workplace supports do not automatically meet the support needs of workers with severe disabilities. Many people with disabilities were not working before the establishment of supported employment



and many more still are unemployed due to a lack of services. However, this does not mean that individuals cannot benefit from the assistance provided by different support resources; it only implies that some kind of help is needed in order to solicit that assistance in a meaningful way to meet particular support needs. The job coach is the one constant person who possesses the skills to identify and develop support resources, assist with accessing services, evaluate their effectiveness, and arrange alternative provisions as the need arises.


Consumers need to choose who will help them and how assistance will be provided—and be able to change their mind if they like—while maintaining a “circle of support” from their job coach who is available to assist with orchestrating or providing whatever supports are desired. The job coach’s role becomes much more refined in that he/she must:

- be knowledgeable of a variety of different types of supports,
- share information with consumers to make informed choices,
- be skilled at helping to access any assistance the consumer wishes,
- provide support themselves when other options are not available or when the consumer prefers his/her help, and
- monitor the ongoing use of a support and arrange alternative assistance should the need arise.

Effective service delivery requires the reliance on a combination of community, supervisor, coworker, family, and human service supports to be employed concurrently or at different times, for the same or for different support needs. The juggling of these many resources while ensuring that a consumer’s support needs are met is a function that falls naturally within the traditional role and special abilities of the job coach.

## Summary

The decision to use community and workplace supports in supported employment service delivery is a personal choice that should be made by the in-

dividual consumers in relationship to each of their specific support needs. It would be a disservice to provide consumers with anything less than all available information concerning all possible support options. 

## Notes

1. The VCU–RRTC Natural Support Transition Project is a 3-year demonstration project funded by the United States Department of Education, Rehabilitation Services Administration, for the period beginning December 1992 through December 1995 to develop, implement, evaluate, and disseminate a natural supports approach for achieving competitive employment outcomes for young adults with severe disabilities who are transitioning from school to work. Individuals served by the project are between the ages of 18 and 25 and have a variety of disabilities, including mental retardation, mental illness, traumatic brain injury, cerebral palsy, and speech, hearing, and visual impairments. The project works closely with local rehabilitation, education, and mental health/mental retardation agencies in Richmond, Virginia, and the surrounding areas of Chesterfield, Hanover, and Henrico Counties.

2. A PASS Plan, or Plan for Achieving Self-Support, is a Social Security Work Incentive that allows a Supplemental Security Income (SSI) recipient to set aside money for a specified period of time for the purpose of accomplishing an employment goal (Prero, 1993; Social Security Administration, 1988).

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## 1995 Postsecondary LD Training Institute

The Seventh Annual Postsecondary Learning Disability Training Institute, sponsored by the Postsecondary Education Unit of the A.J. Pappanikou Center on Special Education and Rehabilitation at The University of Connecticut, will be held June 14-17, 1995.

Specifically designed for postsecondary providers of services for people with learning disability (LD); postsecondary administrators, faculty, and staff; private consultants; and counselors, the intensive 3 and 1/2 day conference will focus on helping concerned professionals meet the unique needs of college students with LD.

Nine conference strands will be offered, addressing such topics as adults with ADD/ADHD, math and LD, providing LD support services in 2- and 4-year colleges, developing LD policies and procedures in postsecondary settings, psychiatric disabilities, legal issues, interpreting LD assessments, learning strategies, and faculty awareness training. An additional Pre-Institute Conference will be held on June 13, 1995, and is designed for service providers of adults with LD (e.g., adult educators, social workers, literacy volunteers, secondary personnel). Speakers will address such topics as employment issues, legal issues, adult LD assessment, instructional strategies for adults with LD, advocacy skills, and transition to college and work.

For additional information and conference brochures, contact: The Connecticut Postsecondary Disability Technical Assistance Center at the University of Connecticut. Telephone: (203) 486-0163/0273.





# "Project Employ: Rehabilitation Services Facilitating Employment of Individuals with HIV/AIDS"

*In 1993, the Centers for Disease Control and Prevention (CDC) reported 103,500 new cases of Acquired Immune Deficiency Syndrome (AIDS) among people in the United States over the age of 13, an increase of 111 percent over the cases reported in 1992.<sup>1</sup> While this increase resulted from the expansion of the AIDS surveillance case definition in 1993, it is significantly higher than the CDC's anticipated estimate of a 75 percent increase. HIV/AIDS is now ranked as the sixth leading cause of death among people aged 15-24, and 76 percent of all AIDS cases occur among adults aged 25-44: people in their most productive and employable years.<sup>2</sup>*

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**H**IV, the virus that causes AIDS, attacks the body's white blood cells (CD4's) which play a key role in the immune system. As time passes, the body loses CD4's and is unable to defend itself. While the average person has a CD4 count of 1,000, for people with HIV this count decreases by an average of 85-100 cells per year. Generally, AIDS-related diseases do not develop until CD4 counts fall below 300. A person can be infected with HIV and not show any symptoms of infection on the average for 5-8 years.

As the CD4 count begins to drop, an infected person may develop thrush, oral hairy leukoplakia, herpes zoster (shingles), or idiopathic thrombocytopenic purpura. Weight loss, chronic weakness, diarrhea, fever, and fatigue are common. In women, chronic yeast infections are also an indication of declining CD4 counts. Common opportunistic infections which occur when a person has progressed to the final AIDS stage include pneumocystis carinii pneumonia, Kaposi's sarcoma, tuberculosis, mycobacterium avium-intracellular infections, toxoplasmic encephalitis, cryptococcoses, cytomegalovirus infections, herpes simplex, and cryptosporidiosis. In addition to the physical attributes, HIV creates a number of psychological problems, including anger, depression, mental fatigue, fear, and guilt.<sup>3</sup>

With today's medical treatments, people with HIV are living and working longer. For the people who have HIV, half are projected to take more than 10 years to develop AIDS.<sup>4</sup> With

medical treatment, they can manage the infection as a chronic, long-term condition similar to many other medical conditions. Vocational rehabilitation (VR), instituted in a timely manner, can play a significant role in enabling the person with HIV/AIDS to continue as a vital member of the work force.

The primary differences between HIV/AIDS and other chronic illnesses are the tremendous social stigma attached to HIV and the perception that all infected persons are going to die. In addition, many healthcare providers carry negative attitudes about some of the subgroups of the population which are most affected by HIV. All too often, people with HIV/AIDS are neither referred for rehabilitation nor do they receive services because of these factors. Yet, studies indicate that *both medical and vocational rehabilitation have an important role to play in helping the person with HIV/AIDS maintain a healthy and productive lifestyle.*<sup>5</sup>

Functional deficits, such as general deconditioning and decreased endurance, cognitive deficits (confusion, poor memory), pain, fatigue, and hemiparesis (muscular weakness affecting one side), can be reduced through medical rehabilitation. Physical therapy can assist with conditioning, strengthening, and pain management, while occupational therapy is important for teaching activities of daily living, as well as providing education in energy conservation and work simplification techniques. Speech therapy is important for persons with aphasia and other conditions affecting speech and breathing. As diarrhea and weight loss are significant problems for many people with HIV/AIDS, nutritional counseling is crucial. Finally, psychological counsel-



ing, therapy, and stress management can all be useful tools in helping to deal with the emotional difficulties which arise in persons with HIV/AIDS.

It is not uncommon for persons, when first learning of their HIV status, to contemplate inappropriate changes in job status because they are unaware of their rights. For example, many infected individuals are unaware that they are covered under the Americans with Disabilities Act (ADA) and the Rehabilitation Act, nor do they know about their rights under Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI).

Just as with other chronic diseases, employees with HIV/AIDS can work quite well when appropriate job accommodations are made. Yet, many HIV+ individuals who are employed often leave their current jobs without negotiating accommodations with their employers. Others may be reluctant to consider taking a job, regardless of how well they feel, because of the potential impact on their disability benefits. The VR counselor can be an important advocate for both employee and employer by providing much needed education to employees regarding disability rights and assisting employers in instituting necessary job adjustments.

Frequently, the infected employee is hesitant to reveal his/her HIV+ status and needs assistance in discussing this issue with his/her employer. Without adequate support, the infected employee may quit, get fired, or reveal his/her status in a less than appropriate manner. The VR counselor can help the employee make this important disclosure. The level of discrimination attached to HIV/AIDS, however, requires the VR counselor to be highly attuned to the confidentiality of the infected employee.

Finally, a number of HIV+ persons come from economically and socially disadvantaged backgrounds. A history of substance abuse is common. The diagnosis of HIV can be a real motivator to some infected persons to "become clean" and "do something" with their lives. While many people with HIV/AIDS are highly motivated to

work, they will need such basic skills as how to read the classifieds and how to handle a job interview. As one VR counselor specializing in HIV/AIDS described it, these individuals require the counselor to be proactive and to manage more than counsel.

***Just as with other chronic diseases, employees with HIV/AIDS can work quite well when appropriate job accommodations are made.***

The American Rehabilitation Association, formerly the National Association of Rehabilitation Facilities, is currently involved in a 3-year project to design a model for the early delivery of vocational rehabilitation services to people with HIV/AIDS before AIDS-related functional limitations occur. As *Project Employ* reaches its mid-point, the research staff has completed a series of surveys and focus groups. In addition, the project established demonstration sites in Baltimore, Maryland (IMPACT at the Sinai Rehabilitation Center), and Grand Rapids, Michigan (Project HOPE), to provide VR services to people with HIV/AIDS. Findings from the first 18 months of this project have helped to identify employment barriers and some possible solutions.

## **Project Participants**

*Procedure:* At the end of the first year, 56 participants were enrolled for services at the Baltimore site and 9 were enrolled in Grand Rapids. Prior to receiving VR services, case managers interviewed each person to collect extensive information concerning health, vocational, educational, and social histories. Due to fatigue or memory loss, many participants were not able to an-

swer all questions completely. The available data were compiled and analyzed in order to establish an overall profile.

*Results:* The average *Project Employ* participant was a male (79 percent), in his mid-thirties, showing some symptoms of disease. With a mean CD4 count of 379, it was understandable that fatigue was the most frequently reported symptom. Modes of transmission were primarily intravenous drug use (IDU) and male to male sexual activity.

Over two-thirds (70 percent) of participants had a high school diploma or less. Nearly all of the project participants were mobile (96 percent) and half lived alone. Relying primarily on SSI, SSDI, or other forms of disability payments, 78 percent of the individuals had an income of \$7,000 or less. When asked about loss of employment, 11 of 26 individuals reported losing their most current jobs as a result of HIV, either from discrimination against the disease and/or sexual orientation or a decreased ability to perform job functions.

Twenty-seven percent of referrals were determined ineligible for services or dropped out of the program. It was not uncommon for the average participant to miss one in three appointments with case managers or counselors. From the 65 participants at both sites, 21 received Individual Written Rehabilitation Programs (IWRP's), 4 saw a physiatrist, 12 had completed vocational evaluations, 8 began employment training, 2 were sent to a drug dependency program, 1 started college, 1 began counseling, and 1 began cosmetology school. Sixteen people were referred for electronics, printing, or micrographics training.

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Many of the participants in the first year contacted *Project Employ* regarding issues around disclosure, disability benefits, and rights under ADA. The motivation to work was high, even if it was for a part-time job or a volunteer position. In Grand Rapids, a hospice patient who wanted to do something productive with the time he had left was given a 2–4 hour a week job working as a receptionist for the area AIDS service organization (ASO). The job increased his feelings of self-worth and enabled him to leave the hospice. Even though this man was able to work for only 3 months before his death, the quality of his life was greatly improved.

***The questionnaire addressed issues surrounding eligibility and range of services, as well as barriers to service.***

*Project Employ* conducted surveys relating to the use of rehabilitation services for people with HIV/AIDS, for state VR agencies, ASO's, and members of the American Rehabilitation Association. Outlined below are the results of the three surveys, as well as the findings from the focus groups for persons with HIV/AIDS.

### **State VR Survey**

*Method:* A survey form was sent to all 50 state VR agencies and to 33 state agencies for the blind and visually impaired in an attempt to understand how VR services are being provided to persons infected with HIV. The questionnaire addressed issues surrounding eligibility and range of services, as well as

barriers to service. Eighty percent of the agencies surveyed responded.

*Results:* The majority of the agencies (75 percent) do not consider HIV or AIDS a primary functional limitation. This means that the VR applicant must have some other limiting factors, such as cognitive deficits or physical deconditioning, in order to be eligible for services. In addition, agencies reported staff fears, anxiety, and social stigma as primary barriers to service. Respondents did not appear to be aware of serving many HIV+ persons, as 28 percent reported seeing between 0–2 persons for the preceding 6-month period. (Given the HIV+ individual's right to confidentiality, the numbers of those receiving services is likely to be under reported.)

### **American Rehabilitation Association Member Survey**

*Method:* An informational survey was sent to 318 comprehensive rehabilitation facilities (CRF) and to 84 VR providers, all of whom were American Rehabilitation Association members (response rates were between 88–100 percent). A detailed followup questionnaire was then sent to the 63 members who indicated that they treated persons with HIV/AIDS.

*Results:* For the 34 respondents to the followup survey, physical therapy (83 percent) was the leading service provided, followed by benefits counseling (37 percent), worksite modification (27 percent), and work hardening (10 percent). Respondents identified lack of funding (52 percent) being the greatest single problem related to service provisions for persons with HIV/AIDS. Other problems included stigma and staff fears, lack of community referral base, and lack of motivation for some to follow through with rehabilitation.

### **ASO Survey**

*Method:* A survey questionnaire was randomly sent to 481 ASO's across the country in order to determine what types of services they currently are providing (including job related services);

how familiar they are with the rehabilitation services available for people with HIV/AIDS; and, according to their experiences, what are the major barriers to employment for individuals with HIV/AIDS. Results are based upon 225 returned questionnaires (a 54 percent response rate).

*Results:* ASO's describe the population they serve generally as adult, homosexual/bisexual males or IDU's. Women and other minority groups were specifically targeted in several organizations; thus, all groups except youth and children were represented. Types of services offered by most organizations included (in descending order) resource information, outreach, advocacy, support groups, nutrition information, social services, psychological counseling, disability benefits counseling, newsletters, transportation, HIV testing, and financial assistance. Only 34 (16 percent) of the ASO's provide any type of job related services, primarily job counseling.

Rehabilitation services that ASO's were most familiar with include residential services, physical therapy, vocational rehabilitation, and occupational rehabilitation. The types of programs/services that ASO's suggested to help individuals with HIV/AIDS find or maintain employment included flexible schedules, job sharing, work at home, job accommodations and enforcement of ADA in the workplace, temporary or part-time employment, job bank, job training or retraining, and employer/employee education.

### **Focus Groups for Persons with HIV/AIDS**

Thirty-five people with HIV/AIDS (20 males and 15 females) have participated in nine focus groups (three in Grand Rapids, one in Baltimore, three in New Hampshire, one in Vermont, and one in Newark, New Jersey). Participants included persons who were infected by all modes of transmission; white, African American, and Latinos; employed, unemployed, and disabled; and residing in cities, suburbs, and rural areas. At least 24 (68 percent) have



already been diagnosed with an AIDS-related illness.

Findings include the following:

- Persons who are currently on disability are hesitant to seek employment as they are concerned that it will jeopardize their benefits.

- The prime motivators for being employed are to reduce depression and to retain health insurance. Financial concerns ranked third.

- Working individuals who are worried about disclosing their HIV status at the workplace experience extreme stress. It is not uncommon for this to lead to the infected individual leaving work on disability.

- Many participants who were working believed that the Americans with Disabilities Act would have little benefit for them in their current work situation.

- Fatigue is a major issue for many HIV+ persons. Many people would like to work part time, short term, and/or in a job with little stress. Two focus groups recommended that job banks be established for persons with HIV/AIDS.

- Many participants expressed an interest in jobs which they thought were fulfilling or had personal meaning to them. Many were interested in helping others who were in a similar situation.

- A certain segment of the HIV/AIDS population views whatever time they have left as "retirement" and has no interest in working.

- Persons who disclose their HIV status are experiencing discrimination in the workplace and in hiring practices.

In coordinating the focus groups, a number of ASO's were contacted. Case managers expressed a serious need for information to help them in working with HIV+ persons. The ASO's wanted to know more about ADA and how to advise HIV+ persons on the basics of disclosing—how to get free legal advice and whether they should accompany the individual when he or she discloses. They had little knowledge of their state's VR programs and what help these programs could provide.

Focus groups are currently underway with employers and employees. Preliminary findings from talking to employers indicate that companies,

even if they have policies on employees with HIV/AIDS, do not necessarily create an environment where the infected employee feels comfortable in disclosing his/her HIV status. Consequently, employers seldom know that an employee is infected until it is often too late to provide adaptive measures.



## Discussion

The majority of *Project Employ* first-year participants have had disease symptomatology for some time. Consequently, the disease progression, in some of them, would be so advanced that the role of VR would be very limited. In addition, many of the first-year participants have had serious issues with substance use. For these individuals, employment difficulties had little to do with HIV/AIDS and more to do with substance use.

In a few cases, referring agencies sent persons to *Project Employ* shortly after the HIV diagnosis was made in conjunction with an AIDS defining illness. In these instances, the person was concerned about returning to work, not because of an inability to perform the job, but rather because of the reaction of the employer and coworkers. These in-

dividuals needed assistance in coping with their new diagnosis, their rights under ADA, and empowerment training. Current employers needed assistance in understanding the needs and rights of their employees and how they could best accommodate them.

The following barriers to rehabilitation services and ultimately to employment were identified as a result of the surveys, VR services in Baltimore and Grand Rapids, and the focus groups.

- HIV/AIDS is not considered a primary functional limitation by most VR agencies, which delays service provision beyond the optimal time for intervention.

- AIDS-related functional disabilities often occur at the later stages of disease, when life expectancy is short.

- Even if a state considers HIV/AIDS as a primary functional limitation, if an order of selection is in place, the person with HIV/AIDS may not be eligible for services unless he/she has another serious disability.

- Many VR counselors have a fear of the disease and are concerned about the social stigma associated with it. Consequently, they may be reluctant to offer much needed services.

- While many people with HIV/AIDS are on disability but are able to work, SSI and SSDI do not provide a sufficient incentive for doing so—lawyers and peers encourage persons on disability not to work as this could jeopardize benefits.

- Some persons with HIV/AIDS have little interest in working, as they view their remaining time left as "retirement years," while others have a spotty work record due to a history of substance abuse.

- Many people with HIV/AIDS are discriminated against in the workplace and in hiring practices. Aware of these activities, many infected employees are reluctant to share their status with their employer.

## Conclusion

While many people with HIV/AIDS are working quite successfully, many



others could and should be working. However, factors such as ignorance and stigma of the disease, lack of job accommodations, limited access to VR services early in the disease process, and the difficulties surrounding SSI and SSDI keep many people with HIV/AIDS at home and out of the work force.

Not many rehabilitation providers consider treatment of persons with HIV/AIDS a priority. This could be due to a combination of reasons: AIDS is viewed by many providers to be a terminal illness, consequently they don't see a need to rehabilitate; staff fears and concerns about the disease; lack of reimbursement of services; and little has been published about the impact rehabilitation can have on the treatment of HIV/AIDS.

Rehabilitation could and should be providing an important role in the care and management of the person with HIV/AIDS, as *Project Employ* currently is demonstrating with individuals who have returned to the workforce. For instance, "George," a 42-year-old, symptomatic male with a CD4 count of 144, was referred to *Project Employ* by a local ASO in February 1993. Within a month, his case was closed due to illness. Maryland's Department of Rehabilitative Services reopened his case in June 1993 for evaluation; by September, George was receiving work adjustment training. Currently, George, with the help of a job coach, is working janitorial services at the Baltimore/Washington International Airport. Despite the advanced stage of illness, George has been successful in his efforts to secure and maintain employment.

To reverse the current trend of providing limited services to this population, the following needs to occur:

- Providers, including ASO's, who treat persons with HIV/AIDS need to be educated about the benefits of early rehabilitation, both medical and vocational, and how to make appropriate and timely referrals.

- Rehabilitation providers, including vocational counselors, must be educated to overcome their fears of the disease and the stigma that accompa-

nies it. They must also be instructed as to the best approach to take in treating these persons.

- Research that documents the importance of rehabilitation, particularly early intervention, needs to be completed and published in peer reviewed journals. Journals for publication need to be those read routinely by providers who treat persons with HIV/AIDS.

***State VR agencies need to recognize HIV/AIDS as a primary functional limitation.***

- Rehabilitation providers must work to educate providers and consumers alike about the importance of rehabilitation in the care and management of persons with HIV/AIDS.

- Rehabilitation providers need to offer services to employers as they work to accommodate the changing needs of the employee with HIV/AIDS.


- State VR agencies need to recognize HIV/AIDS as a primary functional limitation.

Other activities which are needed to help obtain employment and keep persons with HIV/AIDS employed include:

- Change SSI and SSDI policies to accommodate the changing status of this population.

- Educate employers and employees to eliminate fear and stigma. In a "safe" environment it will be easier for an infected employee to disclose his or her status. In addition, the employer should adopt policies which are in accordance with ADA. The employer needs assistance in implementing job accommodations and other special programs which will help the infected employee.

- Provide assistance to persons with HIV/AIDS who are already employed. Such assistance can include: understanding rights under ADA; tips on who, what, when, and how to disclose; and legal counsel. Case managers of the ASO's, providers treating persons with HIV/AIDS (particularly social workers), and counselors at HIV testing centers all need to be trained to assist the infected person regarding employment issues.

- Establish job banks, through the ASO's, which offer full, part-time, temporary, and voluntary positions. 

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# Functional Assessment Procedures for Individuals with Severe Cognitive Disabilities

*The Center for Applied Neuropsychology has had the opportunity to develop a model of performing functional assessment and training staff through a number of demonstration and training projects. The initial project was a 1-year grant funded by the Pittsburgh District of the Pennsylvania Office of Vocational Rehabilitation, which served as a pilot project for functional assessment procedures, report style, and collaboration with referring state vocational rehabilitation (VR) agency counselors. Three additional projects have been funded by the Rehabilitation Services Administration (RSA): a 3-year special project grant in functional assessment and two national training grants. This article discusses the unique rehabilitation needs of persons with cognitive disabilities, describes the process of functional assessment developed through these pilot programs, and presents the implications for rehabilitation practice.*

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## The Challenge of Cognitive Disabilities

Persons with severe cognitive disabilities resulting from traumatic brain injuries (TBI), specific learning disabilities (SLD), attention deficit-hyperactivity disorder (ADHD), and other neurologically based disorders present a difficult challenge to vocational rehabilitation. Due to the multiple disabling conditions (cognitive, physical, behavioral, emotional) that indi-

viduals with cognitive disabilities may experience, rehabilitation success rates are low. It has been difficult for state VR agency counselors to make decisions about eligibility, to assist individuals in setting vocational goals, and to construct a realistic rehabilitation plan. Many people have an extensive history of rehabilitation services and assessment, but are no closer to getting a job.

State VR counselors have reported that standard psychological assessments were of limited use in identifying the obstacles to obtaining an employment outcome. These assessments provided information on intellectual capacity and academic achievement but often failed to address the issues of reasonable vocational goals, possible obstacles, and rehabilitation strategies. When these is-

ssues were addressed, it was still difficult for the individual to incorporate that information into vocational plans.

Even neuropsychological assessments, which provide information about specific cognitive functions, such as memory or attention, are often difficult to translate to real world issues of employment and independent living. Traditional evaluations leave many needs unmet for persons with a cognitive disability and their referring counselors.

Functional assessments go beyond standard approaches, such as neuropsychological tests, and identify functional obstacles to goal attainment, residual job skills, and the specific conditions under which these skills can be utilized (McCue, 1993). Currently, while several approaches to functional assessment exist (e.g., *Functional Assessment Inventory*; Crewe & Athelstan, 1984; *Rehabilitation Indicators*; Diller, Fordyce, Jacobs, et al., 1983), none of these approaches have sufficiently addressed the assessment of cognitive and problem solving demands and abilities. A major shortcoming of most functional assessment instruments has been the restricted range of activities they address (Haffey & Johnston, 1990; Indices,

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1979). In order to assess the impact of cognitive disability on functioning and effectively develop a plan to overcome obstacles to an employment outcome with the individual with a cognitive disability, new procedures must be developed and validated. In a report generated from an RSA funded review, final recommendations included the sponsorship of the development of scales or systems to address functional limitations. Further recommendations suggested that innovative work be done in the development of novel approaches to measurement, and ones that can be developed and researched in the everyday environment (Indices, 1979).

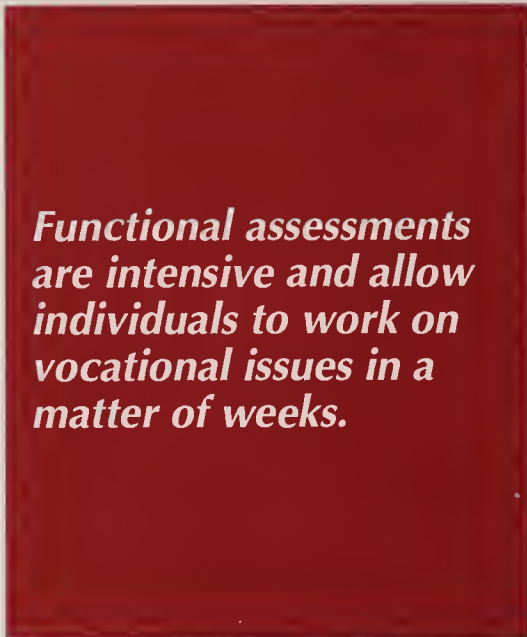
### Limitations of Standard Psychological or Neuropsychological Assessments

Standard psychological and neuropsychological testing is the most frequently used means for assessing persons with cognitive disabilities. Psychological tests measure abstract concepts such as intellectual capacity or personality, while neuropsychological tests, which were developed to determine the presence or absence of brain damage, assess specific cognitive skills such as verbal memory or divided attention. Both types of tests are frequently utilized for the vocational rehabilitation purposes of diagnosis/eligibility and rehabilitation planning.

Unfortunately, for rehabilitation purposes, most traditional psychological and neuropsychological tests were not developed to predict behavior in the natural environment and, consequently, they fail to provide much of the information that is critical for effective rehabilitation planning. While these tests identify manifestations resulting from cognitive disabilities, they are not optimally effective in detailing how these effects interact with task and environmental demands to impact the individual's functioning in real-life situations (Cicerone & Tupper, 1990). In fact, it is possible that results of psychological assessment procedures alone can be

quite misrepresentative of an individual's actual functional level. An individual may function far above or below levels suggested by psychological test results (Naugle & Chelune, 1990).

It is difficult to identify the potential vocational impact of cognitive strengths and weaknesses identified through these more standard assessments, since the demands of the worksite are rarely assessed and integrated into the interpretation of test findings. As a result, planning effective rehabilitation strategies is hampered since the obstacles to be addressed are not clearly delineated.



***Functional assessments are intensive and allow individuals to work on vocational issues in a matter of weeks.***

### Advantages of Functional Assessment

Functional assessment can be defined as a process that enables an individual to identify the impact of his/her disability in real world activities, such as employment and independent living. A good functional assessment determines the individual's strengths and limitations and assists in selecting vocational options consistent with the individual's interests and aptitudes. In order to accomplish this, functional assessment must identify the environmental demands that are or will be placed on the individual, given the vocational goal he/she chooses. Functional assessment specifies the obstacles the individual is likely to encounter in pursuing the goal and suggests strategies that match

the individual's values and skills for addressing these obstacles.

Functional assessment is designed to enable the individual to understand the effect that cognitive strengths and weaknesses have on everyday functioning and vocational options and helps the individual incorporate this information and consider vocational options that will allow for optimal success. In meeting this goal, functional assessment has several advantages over standard psychological assessment and other forms of interventions. Functional assessments are intensive and allow individuals to work on vocational issues in a matter of weeks as opposed to over an indefinite period of time; and, while many programs focus on group activities, functional assessments are individualized. Participants focus on their own goals and aptitudes and map out an individually tailored plan to follow.

In functional assessment, the goals are to:

- identify any obstacles that may affect the individual's vocational goal,
- recognize functional limitations and their relation, if any, to the obstacles, and
- identify functional assets which may be a key to overcoming the obstacles.

Performance on all assessments should be interpreted in terms of the relevant *cognitive* and *behavioral domains* involved, including areas such as attention, memory, receptive and expressive language, information processing, and executive functions (problem solving, planning, initiation, inhibition, judgement, self-monitoring, insight and awareness, self-evaluation, and flexibility).

### The Functional Assessment Program

The following is a list of the programmatic components of this pilot program being demonstrated through the RSA sponsored Special Projects Grant entitled *Functional Assessment of Cognitive Disabilities*. Program components include a pre-assessment staffing, functional interviewing, modified psychometric assessments, questionnaires



and rating scales, cognitive and vocational simulations, naturalistic observations in the work environment, and post-assessment staffing and report. These are described below, along with additional features of the pilot project.

### Pre-Assessment Staffing

Once a referral has been made and at least preliminary background records have been gathered, a pre-assessment staffing is scheduled. This meeting includes the individual who is considering the assessment, any significant others the individual chooses, the VR counselor, and the service provider. The pre-assessment staffing takes place at the site where the assessment will be completed to familiarize the individual with the setting and in finding it.

The goal of the pre-assessment staffing is to allow the individual to make an informed choice concerning participation in the assessment. To do this, consensus among all parties concerning the purpose of the evaluation and the specific referral questions is established. The individual is at the center of this discussion, is in no way a passive observer, and is asked about his/her understanding of the assessment purpose and procedures. If the individual does not have a clear understanding, the information is provided again in a clear, concise way. All information should be provided in a format that the individual can understand and take for future review. If there is clear consensus among all involved concerning the nature and purpose of the assessment, and the individual is in agreement, a starting date for the assessment can be arranged. The consumer is assured that the assessment depends on his/her investment of time and effort and will only be scheduled with full consent. From this early contact the individual understands that he/she needs to be an active participant in the assessment, and that it is in fact designed for his or her self-discovery.

***A functional interview is an extension of the data gathering process that starts with collecting background information.***

### Functional Interviewing

A functional interview is an extension of the data gathering process that starts with collecting background information. It should serve several purposes:

- *To elicit the individual's version of his/her history.* Areas of discrepancy with other sources of information need to be explored.

- *To determine the individual's view of the problems or obstacles he/she is encountering in daily activities.* The nature and cause of the problems, as the individual sees them, should be explored, as well as any strategies and accommodations found effective in dealing with these obstacles.

- *To insure that the individual's goals for the assessment are made explicit and can be addressed through the process.* The individual should be able to restate the referral question. Often the consumer may have difficulty remembering the information from the pre-assessment staffing. During the functional interview the individual should have another chance to review goals and address any discrepancies.

- *To engage the individual as an equal partner in the assessment process and enable him/her to see the assessment as an opportunity for self-discovery.*

- *To identify the individual's vocational goals, which will be addressed throughout the assessment process.*

- *To identify any discrepancies between the individual's perception of problems and actual behaviors history or the report of observers.*

To help elicit and organize the information from the functional interview, the interviewer should be aware that direct questioning of functional abilities (e.g., Do you have any problems with planning and organization?) may not provide valid results for various reasons. Two tactics may be taken in the interview and, to some extent, both should be used. The first is to ask the question directly. For example, if you wanted to know about organizational skills, ask the consumer if he/she has effective organizational abilities. You may have to give examples that pertain to his/her situation, like "Are you able to organize and prioritize the weekly assignments that you have for the four courses you are taking?" While it is important to obtain the perspective of the consumer regarding his/her cognitive abilities and problems, the problems experienced may limit his/her ability to accurately understand and respond to the questions. Because of a cognitive disability involving such areas as comprehension and expression, memory, or self-awareness, the consumer may not be able to accurately appraise and report on his/her abilities in response to direct questioning. This brings us to the second tactic: to question the individual about *how* he/she carries out certain activities of daily life and infer from this his or her cognitive abilities and limitations. For example, Table 1 lists prompts for generating information from the interview on executive abilities.

### Questionnaires, Rating Scales and Behavioral Observation

Rating scales can be given to the consumer and a variety of *independent raters*<sup>1</sup> (with the individual's permission). Rating scales help respondents consider a broad scope of issues and help them organize and report their observations in a consistent fashion. When a rating scale has parallel forms for the individual and an independent



**Table 1.**  
**Interview Questions for Understanding Executive Abilities**

- Do you grocery shop for yourself? If so, describe how you go about this.
- Have you ever planned a party? If so, describe what you did. If not, what do you think would be important things to do in planning a party?
- (If in school) Tell me how you organize your materials, assignments, and projects for school.
- How did you find this place? What did you do to learn how to get here, and then to actually get here?
- Tell me what you feel your strengths and weakness are and why you feel they are either a strength or weakness?
- What is the process you go through in opening, responding to, and filing (storing) your mail.
- Where are the following things:
  - the owner's card for your vehicle
  - your birth certificate
  - your social security card
  - a roll of scotch tape or a stapler in your house
  - the instruction manual for your VCR
- What do you do to remember or store important telephone numbers that you might need on a day-to-day basis?
- Describe the last significant (important, pressing) problem that you solved.

rater, discrepancies become apparent and can be explored.

For a questionnaire or rating scale to be useful, it should be specific to obstacles encountered by persons with cognitive disabilities. Several such questionnaires that have been used effectively are available, such as the *Patient's Assessment of Own Functioning Inventory* (Heaton & Pendleton, 1981) and the *Patient Competency Rating Scale* (Fordyce, 1983), which may be used to identify the impact of cognitive disability from the perspective of the consumer and an independent rater; these scales, completed by the consumer, also have parallel forms, which are rated by a family member on the same dimensions. The use of relatives' forms allows for validation of self-report and may also help identify possible inaccuracies of self-appraisal. Additional scales may be designed to expand upon and quantify performance observations.

## Standardized Testing

Standardized testing provides invaluable information about the consumer's areas of cognitive strengths and limitations. This information can be used to better interpret the individual's performance in the simulations and real-life tasks used in the assessment, increase the consumer's accurate self-appraisal and self-advocacy, and develop recommendations for accommodations to insure that these incorporate the individual's areas of strength.

A neuropsychological assessment is recommended for individuals who have not had recent comprehensive testing. The combination of standardized assessment and tasks that are more directly related to everyday activities (simulations, situational assessments) offers more complete information for rehabilitation planning. For a review of neuropsychological procedures, see

Lezak (1983) or Wedding, Horton and Webster (1986).

To draw accurate conclusions from the functional assessment requires careful review of standardized test data and hypothesis testing during the subsequent, nonstandard assessments. From the testing, the evaluator hypothesizes about which cognitive or behavioral domains present functional obstacles for the individual. Once a potential cognitive limitation has been identified, the evaluator in functional assessment needs to vary the task demands to "control" for that cognitive problem and determine the possible contribution of other cognitive skills. For example, if the evaluator believes that the individual's receptive language is an obstacle, they will watch for a pattern of performance in a number of assessment settings. The evaluator needs to control for the potential receptive language problem by assuring that the individual understands what is asked of him or her. Then the evaluator needs to determine if, for example, attention or memory might be also be affecting the individual's performance.

## Simulations

Simulations and role playing of real-life activities are used to determine how an individual utilizes cognitive skills to resolve real-life problems. These activities require the individual to deal with multiple priorities, unforeseen circumstances, and interpersonal interactions. Table 2 presents a brief description of some of the simulations developed for use in the pilot project.

## Situational Assessment

Situational assessments are completed by observing how the individual functions over a period of time in a real-life environment. These short-term, real-life experiences can be arranged through temporary employment, often through the use of a temporary personnel agency. Volunteer work or short-term employment arranged through family or friends can also be considered.



**Table 2.**  
**Sample of Cognitive-Vocational Simulations**

**CLERICAL SIMULATION:** On this task the individual performs a clerical task which involves organizing a large pile of cards containing catalog information. Cards of various colors are organized in different ways. For example, white cards are sorted alphabetically by name, while blue cards are sorted in alphanumeric order by invoice code. During the first hour, the individual receives three phone calls and is asked to take a message. The individual is required to keep track of the time and, after 1 hour, take a brief break to deliver the messages to a designated staff member. The individual is also asked to count the number of cards indexed and report it to the staff member as well. The clerical simulation is designed to measure concentration, divided attention, learning complex rules, organization of materials, comprehension of instructions, and problem solving.

**ACADEMIC SIMULATION:** This task is used with individuals whose goals are to attend college or a vocational training program. The individual watches a videotaped lecture, takes notes on the lecture itself, and completes a brief quiz about the information at the end of the hour. Individuals are also asked to read a chapter in a beginning college-level book, outline the chapter, write a one-page summary of the main ideas presented, and take a brief quiz on the material. This simulation measures ability to discriminate essential information, learning of new academic material, written expressive language (essay), concept formation and integration, organization and planning, and study skills.

**ROUTE FINDING/JOB SEARCH SIMULATION: (STATE OFFICE BUILDING):** The individual is required to locate the state office building and the office to apply for state jobs. Maps, verbal, or written directions are offered, but are not supplied unless the individual requests them. Individuals are asked to bring back information on two jobs that are of interest and reasonably matched to their skills for which they might wish to apply. The individual is also asked to pick up an application form and bring it to the interview fully completed. This simulation measures route finding, planning, anticipation, self-evaluation, social interactional skills, goal formulation, use of resources, and ability to complete an open-ended task.

**AMERICAN ADAPTATION OF THE MULTIPLE ERRANDS TEST (AMET):** The AMET (Aitken, Chase, McCue, and Ratcliff, 1993; Shallice and Burgess, 1991) requires the individual to shop for a standard set of six items as quickly and cheaply as possible in a relatively small, contained shopping area, while obeying several rules. He or she must also mail to the evaluator a postcard containing information which can reasonably be obtained during the shopping trip; the consumer must then rendezvous with the evaluator at a specified place and time. The individual is not told how to acquire the information, and some task requirements are only implied. The AMET measures planning or multiple tasks, ability to keep within rules, organization of time and money, trial and error learning, novel problem solving and generation of alternatives, (prospective) memory for appointments, and self-evaluation and self-correction.

Situational assessments can be designed to match the demands of academic or vocational training environments if the individual's vocational goals include training. Arrangements can be made for individuals to sit in on classes on a timelimited basis. They can attend professional seminars or continuing education courses to assess their response to training at this level.

While it may not be necessary to place the individual in the environment of the ultimate vocation, it is important for the individual to be placed in a situational assessment that is related to the vocational goal. The individual may have an easier time understanding how his or her performance in this setting will be related to performance in meeting the vocational goal. Even if the placement for situational assessment is unrelated or only marginally related to the vocational goal, valuable information can be obtained. Cognitive endurance, ability to adjust to new demands, interactions with coworkers and supervisors, and problems with transportation or break times can all be observed during any situational assessment. In the instance where the placement is in an unrelated area, it may require additional counseling and debriefing to help the individual understand the relationship between his/her performance in the situational assessment and performance in the goal area. Situational assessment may also provide an opportunity for the individual to try out a job that more closely matches his/her ability than the job identified as the vocational goal, and is therefore an excellent resource for vocational exploration.

### **Observation in the Natural Environment**

One's ability to perform in the natural environment may be markedly different than performance in other settings would predict, and should be assessed through direct observations, which can be completed at the individual's job site, in the classroom, or in the home, depending on the person's level of functioning.



**Table 3.**  
**Suggested Questions to be Addressed by Functional Assessment**

1. Did the individual attend to directions?
  - Did the individual attend after cuing?
  - Did the individual attend initially, then fade?
2. Were the directions understood?
  - Could the individual explain the task back clearly?
  - Was the individual able to demonstrate the task?
3. If the directions were not understood initially, what if anything, made the directions more clear?
  - Repetition?
  - Simplifying the language?
  - Breaking directions down into smaller pieces?
  - Providing direction in writing?
  - Using pictures, graphics, or diagrams?
  - Demonstrating the directions?
4. Was the task begun independently or was a cue needed to initiate?
5. Was the task begun prematurely or impulsively before directions were completed and understood?
6. After beginning, how long was the individual able to stay on task before requiring redirection?
7. Why was redirection necessary?
  - Distraction by another activity?
  - Self-distraction?
  - Loss of interest or motivation?
  - Confusion about how to proceed?
  - Forgetting the instructions?
8. Was the individual able to generalize the instructions to a new situation?
9. Was the individual able to seek additional information that was needed?
10. Was the individual able to problem solve when confronted with uncertainty?
11. Was the individual able to persist with the task until completion?
12. Was the task completed in a timely fashion?
13. Was the task completed accurately?
14. Did the individual spontaneously use any accommodations or strategies to help him/herself?
15. Was the individual able to detect his/her own errors?
16. Was the individual able to self-correct errors?
17. Could the individual correct errors with feedback?
18. Was the individual's overall rating of own performance accurate?
19. Was the individual able to identify what contributed to difficulties, if any?
20. Could the individual identify any strategies or approaches that would help?
21. How was the task completed on repetition?

Performance on tasks in the real world or on simulations of these tasks can be difficult to quantify or even to describe, especially when dealing with covert cognitive skills. Table 3 contains a list of suggested questions that provide a framework for cognitive behavioral observations, both in the natural and in the testing/evaluation environments.

### Post-Assessment Staffing

Following the assessment, a meeting which includes the individual, significant others or advocates (as requested by the individual), the referring counselor, and the assessment staff should be held. In this meeting, a summary of findings should be presented as a review of information that has already been discussed with the person and the counselor over the course of evaluation. The response to the initial referral questions posed in the pre-assessment staffing should be explicitly discussed. A brief written summary or table of key findings and recommendations should be distributed to make the information more accessible and available for the individual's review over time.

Acknowledging that one of the major obstacles to successful vocational integration of persons with cognitive disabilities is difficulty in accurate self-appraisal, the most important outcome of the functional assessment process is agreement among the individual, the rehabilitation counselor, and the evaluator concerning key issues, such as: the answer to the referral question; cognitive strengths; cognitive limitations; functional obstacles; vocational options; vocational impact; and recommended strategies and accommodations for addressing obstacles to goal attainment.

To achieve consensus, direct efforts must be made towards this end. Individuals can be involved in the process by using daily feedback sessions for their input. This time can be used to acquire information about performance and skills and to relate it to vocational goals. A "product monitoring" approach, in which the outcome of their work can be addressed, as opposed to judging



performance, may be less threatening and allow for greater growth.

Questions that can help the individual focus on productive change and information gathering include:

"Were you satisfied with the outcome of that task?"

"Are there things that would help you if you did it again?"

"Is that kind of task related to the work you want to do?"

"Is there any way to get around it?"

"Are there any other options to consider?"

It is important that the VR counselor is included during the functional assessment process and that information or recommendations do not come as a surprise during a post-assessment staff meeting. Frequent brief phone calls to keep the counselor informed of findings and possible recommendations allow the counselor's input to be incorporated throughout the assessment. Regular communication between the referring VR counselor and the consumer during the process is also advocated.

During the post-assessment staffing, formal agreement is established concerning changes in vocational goals and recommendations for accommodations or interventions. If new questions are raised, or if new directions are identified, the final report produced after the meeting can incorporate these issues.

Consumers should be asked to summarize their understanding of assessment findings and recommendations; should clarification be needed, it can then be provided. Sufficient time should be allotted to respond to questions from all participants.

## **Functional Assessment as an Intervention**

Even the most functionally oriented psychological or neuropsychological assessment may fail to help the consumer develop insight into the impact of disability in everyday life. This occurs for several reasons:

- The person being assessed may get little feedback about performance during the assessment session.

- The individual may have difficulty relating the assessment tasks to real-life tasks.

- When the report is delivered to the rehabilitation counselor, it may be difficult for both the counselor and the consumer to understand.

- Finally, because of the nature of cognitive disabilities, the consumer may have difficulty understanding new information and applying it to everyday or work activities. This is possibly due to the problems with language, information processing, memory, and self-evaluation that are common to many persons with cognitive disabilities.

The functional assessment process allows the consumer to participate in a wide range of experiences and to obtain immediate information about strengths and weaknesses, information that is useful as it relates to employment and other aspects of his/her life. With the right kind of feedback, individuals with specific weaknesses, such as in language, memory, information processing, or self-evaluation, learn the extent of these difficulties and understand how these weakness may manifest in a real-life situation.

Following the completion of each structured activity or simulation, a staff member interviews the consumer to identify self-perceptions of performance. The consumer is asked to be specific about areas of competence and weakness and is assisted in keeping a written or audiotaped record of assessment tasks, results, and insights. The staff person discusses the rationale for the activity and offers insight on areas of apparent strength and/or weakness. Possible strategies for accommodation or improving performance are also discussed.

Care is taken to match language and information processing demands to the consumer's ability. Sometimes, a videotape of the activity is reviewed with the individual. Emphasis is placed on the individual's strengths, as opposed to deficits. Information learned in each simulation is added to information learned earlier, thus reinforcing specific areas of strength and weakness with new data. Eventually, consumers

are able to better appreciate their strengths and weaknesses and, therefore, are better prepared to apply what they have learned about themselves towards their employment decisions.

Every effort is made to help the individual focus on the obstacles identified, not on deficits. This strategy creates an expectation of equal participation rather than one of passive assessment and diagnosis and reduces the natural tendency that everyone has to become defensive when being tested. The functional assessment process fosters self-discovery, adaptive change in the individual, and a readiness to implement effective vocational rehabilitation plans. It also helps the individual to see the environmental factors which can affect his/her vocational outcome and shows how to develop strategies to deal with these issues.

## **Pilot Project Results: Participant Outcomes**

Functional assessment and outcome data are available for a total of 21 people who participated in the pilot functional assessment. Of this group, there were 10 men and 11 women, with average educational level of 12.3. Two persons were African-American; all others were Caucasian. Upon referral, seven participants were employed in some capacity and three were volunteering. The others were unemployed or in transition and considering various options. All those who were employed at the onset of the program reported dissatisfaction with their current jobs due to underemployment, problems performing adequately on the job, or chronic, short-term employment. At the end of the project, 12 participants were working, 3 were volunteering, and 3 had entered formal vocational training programs. Of more interest, however, are the relative shifts made by individuals over the course of the project: six persons moved from unemployment to competitive employment, two moved from unemployment to a volunteer position, and one moved from unemployment into a suitable training program. Additionally, another



individual left a dead end job for a training program consistent with her interests and aptitude. In total, of the 21 people assessed, 10 achieved clear-cut vocational gains as measured by rating of vocational activity pre-assessment versus post-assessment.

The remaining participants, for which there was “no change” in vocational status, represent an even more interesting outcome in functional assessment. For many of these individuals, change came in the form of acceptance of current circumstances as a rewarding and reasonable activity (e.g., choosing to remain employed in a grocery store and pursue on-the-job managerial training), or manipulation of system variables (family or employer expectations, for example) so that inappropriate goals of vocational change were lifted.

In order to capture these changes across the project, clinical ratings were assigned on a four point scale, representing:

- 1) a significant shift toward more realistic goals or acceptance of current position;

- 2) some change in behavior or a significant increase in verbalization toward more realistic goals;

- 3) minimal change; or

- 4) decreased willingness or ability to consider realistic vocational options.

Of those participants whose overall vocational status remained the same (e.g., employed vs. unemployed), eight made some positive change toward accepting their current circumstances. Only two were felt to have remained relatively unchanged, meaning that their ongoing status may not represent their optimal choice.

Using the same rating system to evaluate change over the course of involvement for the group as a whole, 12 participants were felt to have made fairly dramatic shifts in orientation or awareness of problem impact, and 6 were judged to have made some change in awareness. Only three were evaluated as having made minimal or no change. None of the participants appeared to have become more reluctant to consider vocational options or in any other way had a negative therapeutic outcome as a result of partici-

pation. In summary, results of this pilot project were felt to have direct impact on vocational choice and outcomes.

## Case Illustration

Steve, a 20-year-old white male with a history of early life brain trauma, is referred by the local office of the state VR agency for functional assessment. He has been working in a retail store, providing stock assistance in a supported work setting but expresses interest in completing college and obtaining a well paying managerial job in an office setting. His stated interests include photography, hospital work, and emergency medical technician (EMT) training.

His functional assessment included review of recent, comprehensive neuropsychological evaluation; interviews with high school teachers and recent tutors used as he attempted EMT training; multiple situational assessments and informational interviews with providers on applied training programs; and a jobsite evaluation. Additionally, family members were interviewed and old records were reviewed.

Previous to his current job, Steve had spent 3 years in a vocational technical training program for EMT's, with minimal progress toward completing any minimal criteria. He had attempted to enroll in a local community college, but was discouraged from applying after being unable to complete the tests for the remedial, pre-college coursework. In addition to these problems, Steve also experienced multiple problems in interpersonal relationships, particularly inappropriate and disinhibited verbalizations toward others, abrupt and tangential personal questions, and a great deal of difficulty remaining focused on topics and activities at hand. His family additionally reported great concern over his poor social judgement and his being very influenced by peers. Finally, Steve appeared to have little appreciation of the ways in which these factors related to his unhappiness with his vocational status and he was unable to identify any personal goals or life plan to move him toward a better alterna-

tive. His general intellectual functions measured in the borderline range, while academics were approximately at the fourth grade level.

Throughout the assessment, every opportunity was taken to assist Steve in comparing his strengths and interests with vocational options and requirements for successful education and for long-term employment in various fields. Over the course of the assessment, Steve made a decision to pursue training as a nursing assistant in the special needs program of a local community college.

A vocational impact table was prepared for several job options; the table relevant to his chosen career field is shown on the next page. Note that the table begins (left column) with a brief abstract of the job tasks, taken from the *Dictionary of Occupational Titles*. The table then identifies probable functional limitations, as indicated by functional assessment. The third column integrates information from the first two columns and lists the vocational impact of functional limitations *for the particular job being considered*. Under “rehabilitation strategies,” specific recommendations are presented that respond to the vocational impact concerns.

The vocational impact table guided discussions with Steve regarding identified areas of weakness, how those might affect a job in the identified field, and some suggestions to accommodate those issues. These efforts were successful in assisting Steve in understanding how his career aspirations were not a good match with his abilities, which resulted in the decision to pursue specialized training in which he had both an interest and a good chance of finding success. This example supports a primary outcome of good functional assessment, which is to align consumer goals with vocational options so that the individual succeeds in the chosen job and also feels good about making the choice. Had a more traditional approach been taken, Steve may have been told that his goals were “unrealistic,” he would have been asked to choose among several fields he perceived as “low-level,” and he would

**Table 4. Implications for Specific Job Demands**

Vocational Objectives	Functional Limitations	Vocational Impact	Rehabilitation Strategies
<b>NURSING ASSISTANT:</b> Answers signal lights. Bathes, dresses, and undresses patients. Serves and collects food trays. Transports patients. Changes bed linens, runs errands, and answers phones. Cleans and sterilizes supplies. Dusts and cleans patient's room.	Limited reading and writing skills.	May have difficulty with certain academic requirements of a training program.	Provide ongoing academic supports with emphasis on reading and writing assignments.
	Expressive and receptive language.	May make mistakes in understanding orders given to him.	Overlearn procedures and provide close supervision.
	Poor memory.	May forget what he needs to do unless it is written down or routine.	Use a structured form that allows Steve to write down his assignments and/or job duties in an organized manner.
	Limited ability to comprehend or process complex information.	May make errors due to failure to understand directions.	Keep the job duties routine, avoiding activities that require novel problem solving. Having job duties written down will be helpful. May benefit from writing down procedures for using machinery, especially if the machine is used only infrequently.  Steve will do best in an environment where there is a supportive supervisor nearby to monitor his work and provide corrective feedback when necessary. May be helpful to ask Steve to repeat instructions after they are given to him.  On-the-job training may be necessary upon completion of a training program.
	Limited social judgement and insight.	May not read subtle social cues.  May respond inappropriately to patients.  May comment inappropriately about job duties, salary, and benefits.	Close supervision and feedback in regards to appropriate social behavior in a work setting, especially when interacting with hospital staff.
	Poor executive skills—initiation, planning, organization, self-evaluation	May fail to identify areas in which he has difficulty.  May make errors and fail to doublecheck work or correct problems.  Unless routine, may be unable to organize and prioritize work needing to be done.	Recommendations are for close supervision and clearly defined job tasks  Assign tasks that are routine and overlearned, avoiding "management" activities, such as organizing a room or deciding on how a job could be done differently or more effectively.



have entered training or a job with low motivation to succeed, poor self-esteem, and anger at the few options open to him.

## Implications for Vocational Rehabilitation Practice

So what can the reader take away and implement from this pilot project? With the existing constraints on counselor time and resources, it is easy to become overwhelmed at the idea of re-vamping the world of rehabilitation. It is equally challenging to change the world of specialty assessments like neuropsychology, particularly when most readers fall somewhere outside of that world, as consumers of the reports rather than writers of them. All members of the rehabilitation community, however, *can* move toward more functional assessment. Some pragmatic suggestions that can be implemented include the following:

- Identify a way of understanding the cognitive strengths and challenges of the individuals with whom you work, such as the model of cognitive domains described in this article. Post a copy of it on your wall. When observing or thinking about a consumer, consider what you know about him/her concerning each domain. Then think about what you know about the cognitive demands of their everyday life. How do they match up?

- Don't neglect the importance of understanding the cognitive demands that will be placed on the individual. In order to understand the impact of a disability, abilities and limitations must be contrasted with task and environmental demands. Use resources such as the *Dictionary of Occupational Titles*, job descriptions from other sources, discussions with supervisors or training instructors, and job analyses to detail the cognitive task demands that will be placed on the individual (e.g., the degree to which the worker must pay attention and respond to multiple sources of information simultaneously). Use a cognitive domains format, similar to what you might use with a consumer, to organize information about the cog-

nitive demands of a particular job or training program.

- When you make your next referral for specialty psychological or neuropsychological assessment, identify the vocational directions under question by the individual; present referral questions that are directly relevant to the individual's life choices. For example, will his impaired memory be an obstacle on the job? If so, is there any way to get around it? What will be the consumer's needs for accommodation when he/she returns to college, to a 2-year vocational training program, or to a previous job?

Be sure your consumers can understand test results in terms of their areas of strengths and in the context of their everyday lives; and that they understand the impact of their disability. Use vendors and providers to help with this and to insure that you fully understand the functional impact of identified problems or deficits before attempting to devise a rehabilitation plan.

- Ask consumers and their families/friends to talk about everyday activities: Who does the laundry, shopping, planning of dinners, bills, and how do the tasks get done? Look for discrepancies between the consumers' and independent raters' responses; followup to determine reasons for differences.

- Regularly ask consumers to evaluate their own performance on specific job tasks, in job interviews, and in daily living or rehabilitation related activities. Rather than focus exclusively on basic facts—such as, “What did you tell them?” “What did they say?”—elicit the consumers' ideas on how they might do things differently, how others might describe their performance, and what might be effective in improving their performance.

- Change your language when working with consumers and providers. Focus on the demands they anticipate in various jobs or environments and, rather than targeting deficits and impairments, discuss the specific obstacles that consumers face as they approach work and functional independence. Discourage consumers from describing themselves

in terms of personal deficits; substitute real-life characteristics instead.

## How to Arrange and Manage Functional Assessment Services

A single service provider in the community, working closely with the VR counselor, may be able to manage the assessment process. In the special project described in this article, the assessments were managed by rehabilitation psychologists. The standardized neuropsychological testing and all other aspects of the testing were completed by project staff or coordinated by the staff with other agencies in the community. Project staff was responsible for scheduling meetings with consumers and counselors, collecting all relevant data, and developing the final, comprehensive report. Other options include having the assessments managed by a vocational evaluator or the staff of a rehabilitation facility or other community agency.

Functional assessment providers need an indepth knowledge of the characteristics of various cognitive disabilities, the impact of cognitive disabilities on everyday activities, and the domains of cognitive function and the assessment of these domains. In some cases, no one provider will be able to complete all aspects of the evaluation. For example, the provider may be unable to complete a formal neuropsychological evaluation or may not have the resources to complete an assessment at a jobsite. In this case, one provider—working with other providers in the community—may still be contracted to manage the assessment, possibly through authorizations or contracts from the VR agency. The agency responsible for managing the assessment coordinates all meetings and activities, gathers data from each of the other agencies involved, and generates a final comprehensive report. One staff member should work closely with the consumer throughout each component of the assessment. This *assessment manager* should help the consumer review outcomes in each segment of the assessment, usually in cooperation with the staff who administered the assessment. Every effort should be made to



help the consumer apply this information to his/her everyday life and vocational options and to record this information in an accessible format.


To initiate these services in a community, the VR agency may wish to invite proposals from multiple community agencies. An initial workshop explaining the need and the anticipated scope of the service could be offered prior to the submission of proposals.

In some communities, it may not be practical to have the assessments managed by a service provider. In these instances the VR counselor can serve as the assessment manager. The VR counselor can complete functional interviews with the consumer and significant others, collect all relevant records, and interview family members, teachers, employers, and counselors. The VR counselor can authorize standard psychological assessments and, if indicated, may authorize worksite assessments or assessments aimed at real-life skills through community agencies. If this is not possible, the counselor could make arrangements to observe at the worksite, the training site, or in other situations in the consumer's natural environment.

The challenge for the counselor is to integrate information identifying the consumer's functional strengths and weaknesses and determining the vocational impact. The counselor must also help the consumer to understand and integrate the information. Some of these tasks may be difficult for counselors, especially if they have not had extensive experience working with individuals with cognitive disabilities. Other tasks are a very natural extension of the counselor's routine activities and training. With support and technical assistance that may be available from specialists working with persons with cognitive disabilities, VR counselors can become effective in conducting all facets of this assessment procedure.

## Training Opportunities

The Center for Applied Neuropsychology has obtained two RSA-sponsored training grants in the area of functional assessment. *Functional Assessment*

*and the Vocational Rehabilitation Process*, a series of three video satellite teleconferences focussing on understanding the impact of cognitive disability and enhancing the functional utility of standardized psychological and neuropsychological assessments were broadcast nationally in November and December 1993. *Facing the Challenge: Functional Assessment of Individuals with Cognitive Disabilities*, a two-part interactive video satellite teleconference, was aired on August 31 and September 14, 1994. This series featured step-by-step approaches to cognitive skills-based functional assessment, including manageable ways of incorporating functional assessment into everyday rehabilitation practice. For more information on either of these training opportunities, contact the Center for Applied Neuropsychology, 100 First Avenue, Suite 900, Pittsburgh, PA 15222 or call (412) 391-4583. 

## Note

1. An independent rater can be *anyone*—family, friends, employers, teachers, counselors, etc.)—who provides information on the consumer for the purpose of improving services and providing the necessary supports to acquire and maintain employment.

Functional assessments go beyond standard approaches, such as neuropsychological tests.

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## Developing a Transportation System for Individuals with Disabilities on a Rural Indian Reservation

Mike Hermanson  
Barbara Landstrom  
John Domitrovich

*Salish Kootenai College (SKC), located on the Flathead Reservation in northwestern Montana, is one of 24 tribally controlled colleges in the United States. One year ago, SKC realized that it was in a unique position to develop a transportation service for individuals with disabilities who live on the reservation that would greatly increase the vocational possibilities available to them.*

A unique mix of characteristics at Salish Kootenai College contributed to the development of a distinctive transportation system for its students with disabilities—SKC had developed a close working relationship with the Montana State Vocational Rehabilitation Services Division and The Confederated Salish and Kootenai Tribes' Vocational Rehabilitation Project (a tribal rehabilitation service project serving American Indians on the Flathead Reservation), as well as several other agencies providing services to individuals with disabilities; the college had a well-developed motor pool and several years of experience providing



transportation services to students, staff, and other tribal programs; the college had been a leader in developing services to individuals with disabilities for the Confederated Salish and Kootenai Tribes; and the college was centrally located to serve the reservation. This combination of factors created a situation which allowed SKC to develop a plan to overcome a major barrier to employment and rehabilitation on the reservation—transportation.

Because of SKC's involvement in disability issues on the reservation, there was a recognition of the critical need for a transportation system that emphasized access to employment and the necessary services to develop vocational potential in the local area. The Flathead Reservation, which is approximately 60 miles long and 50 miles wide and covers 2,800 square miles, is a very remote, rural area with a number of scattered population centers. It extends into four counties, although Lake County is the primary county involved. In this area, there are nine major population areas. In order to obtain many medical services and evaluation services related to rehabilitation plans, individuals are required to travel to Missoula or Kalispell, which are each located 65 miles from the center of the reservation. The only fixed route system serving the Flathead Reservation is the Intermountain Transportation Bus Lines, which runs south through the reservation between 11:30 a.m. and 1:30 p.m. and north between 7–8:30 p.m. Also, the bus only travels Highway 93 and only stops at one designated spot at each town on this highway. Because the area is near the Mission Mountain Range, the weather can be very hazardous, particularly during the winter when several inches or even several feet of snow are not uncommon. The special geographic conditions of this area create unique circumstances and difficulties for the development of a transportation system.

Other characteristics of the area create special problems for individuals with disabilities. Because this is a rural area, there are few sidewalks; therefore people who use wheelchairs or have

visual impairments have great difficulties in making connections with a transportation system, particularly with the added problem of the winter snow, when they can become very isolated in their homes. Even when individuals have transportation of their own they are likely to live some distance from a neighbor and/or repair facilities. Also, repair services in the area are very limited, and a vehicle that breaks down may not be repaired quickly. The lack of an adequate transportation for individuals with disabilities not only creates inconvenience, but at times causes undue risk as well.

*The special geographic conditions of this area create unique circumstances and difficulties for the development of a transportation system.*

A needs survey conducted by Summit Independent Living Center in Spring 1991 reported that 79 percent of the individuals with disabilities in Lake County surveyed indicated that transportation was an important issue to them. Only 38 percent expressed satisfaction with their current situation. Out of 32 issues, transportation ranked as the fifth highest need of individuals with disabilities in Lake County.

Prior to initiating the proposal that developed the transportation services project, SKC communicated with a variety of tribal and state service agencies who provide services to people with disabilities. These contacts indicated that 300–400 residents of the Flathead Reservation could benefit from a transportation system.

The staff of the Tribe's Vocational Rehabilitation Services Project has also contacted the Mental Health Services of the State and Tribe, the Summit Inde-

pendent Living Center, Job Services, and Mission Mountain Enterprises to estimate the number of people who might benefit from the proposed transportation service. The estimate was that 200–300 people could possibly benefit from the proposed services. Therefore, assuming that not everyone who could benefit from services would apply, the projection of serving a minimum of 100 people the first year of operation appeared reasonable.

On October 1, 1993, with the assistance of a grant award (H235E30070) from the Special Demonstration Projects and Demonstration Activities Program of the Rehabilitation Services Administration, SKC initiated a project to empower individuals with disabilities to maximize their employment option, economic self-sufficiency, independence, and inclusion and integration into society. The development of a unique service delivery system for the area is an outgrowth of one of the major goals of Salish Kootenai College—"to assist with the community development needs of the Flathead Reservation."

Although the project has been in operation only a short time, there is evidence that the new service has opened up a number of vocational and rehabilitation possibilities to individuals with disabilities who reside on the Flathead Reservation. In addition to these services, the project has played a role in developing an interest in the better coordination of all transportation services on the reservation, with more interest being shown in the development of a fully-coordinated transportation system that would meet the needs of individuals with disabilities.

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*Consumer disembarks from one of three special vans purchased for the Flathead Reservation's transportation system.*

## The Consumers

The characteristics of the consumers who have applied for services over the past 6 months present a picture that reflects the problems described above. The two profiles below offer an overview of the problems that are currently being addressed by the transportation program.

The first is that of a Native American woman with a developmental disability who obtained a position in a day care center but did not have the transportation resources to travel the 7 miles from her home to the town where the day care center was located. The newly initiated transportation services have been critical to her ability to maintain employment.

The second profile is of a man in his early twenties with cerebral palsy. A wheelchair and communication board

user, the man is not a tribal member; but because the transportation service is open to all residents of the reservation, he also benefits from this resource. He is able to attend college classes using the transportation services to travel the 10 miles to the college from the town where his group home is located. The opportunity to attend the college classes has opened many opportunities for this young man and his potential vocational outcomes have been greatly expanded.

Others who have been served in the short existence of the program include a person with chemical dependency who needed transportation as a result of not having a driver's license and a person with a heart condition who needed to make a trip of over 120 miles each week and who needed alternative transportation to enable his wife to maintain her em-

ployment. Another individual, who is legally blind, needed transportation to the nearest airport, 60 miles away, for a work-related trip.

## The Services

A point-to-point transportation system was developed for picking up consumers, usually at their homes, and transporting them to their destination, usually their workplace or the facility providing their rehabilitation services. To accomplish this, three wheelchair accessible vans were purchased with grant funds to be used along with a previously purchased van. Rides are coordinated as much as possible; however the current volume and scattered needs of the system make coordination difficult at this early stage of development.

Whenever possible, other available transportation services are used. An example of this is the woman who was able to ride to her day care job on the busses that bring students to Salish Kootenai College.

## The Results

The benefits at this stage of the project are quite limited as the project has only been operational for 6 months. However, a review of the statistical data thus far, indicates the nature of the services being provided. At this point, the project's primary publicity has been through contact with agencies serving persons with disabilities; thus far, seven different agencies have made referrals that have led to a total of 16 people being served. One hundred and fourteen trips have been provided over a distance of 2,405 miles of actual service (average length of trip is 18 miles). However, 2,404 additional miles were needed to initiate trips by the service vehicles, bringing to 36 the actual average number of miles necessary to provide each trip, which can be explained by the remoteness of the area and the geographic distribution of consumers over such a large area.



## Program Issues


Because of the overall need for public transportation on the reservation, the program has received a number of requests for services that are not within the guidelines and requirements of the grant which funds the program. Requests have been made by persons without disabilities—as well as by persons with disabilities—for needs such as medical care for persons who are not in a rehabilitation plan leading to employment or who have recreational or independent living needs. The project has had to turn down a number of these requests due to funding restrictions. However, the project is exploring options of offering such trips for a fee that would cover the costs of the transportation or of coordinating some of these requests with approved trips, if there is room for others and if the additional travel does not inconvenience the eligible consumer. Also, the project seeks other transportation resources and makes referrals as appropriate.

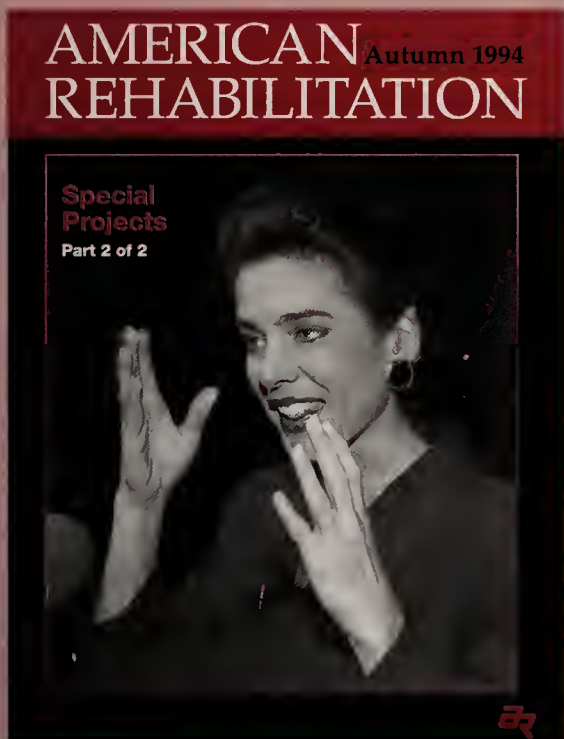
The project has not generated the anticipated number of eligible applicants for services at this time. One problem is that the eligibility limitations of the program are difficult to describe succinctly to the public via advertising. Therefore, the advertising may be confusing and may not be attracting new applicants. Also, in a rural area the acceptance of and use of new programs are slow to develop, as people in such areas tend to rely more on word-of-mouth information when considering available resources. Ideally, there would be one advertised number to call for transportation information. The Transportation Advisory Committee is attempting to establish this.

Also, an expansion of the reservation and area highway system is currently under study; a transportation consultant has been contracted by the State of Montana to explore this issue. The consultant's early impressions are that SKC may be the best alternative to coordinate a public transportation system because of its early successes with the reservation wide education transportation system and the disability transportation

system described in this article. Although it is unusual for a college to coordinate a public transportation system, this demonstrates how rural areas must deal with a variety of problems. A separate public transportation system would be uneconomical; modifying a system that is already in place often is the best solution. The consultant also suggests that such a system could become a training center for other reservation and rural transportation systems because of its link to the college. Such expansion would certainly lead to further program issues.

## Conclusion

Because the project is so new, this article must be limited to a description of the possibilities of the Confederated Salish and Kootenai Tribes Vocational Rehabilitation Transportation Project, rather than a review of results and potential for generalization of techniques. However, it is hoped that the article provides information related to unique problems of rural reservations and a description of the problem solving and creativity necessary to meet such needs. 



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# The Use of Cognitive Functional Assessment in a Psychiatric Vocational Rehabilitation Program

*People with psychiatric disabilities have more difficulty attaining and maintaining competitive employment than any other disability group (Dunn, 1981; Mars, 1990; Rehabilitation Services Administration, 1992). Our success, however, in the vocational rehabilitation of people with severe and persistent mental illness until recently has been disappointing. In their review of research on the effectiveness of psychiatric vocational rehabilitation, Bond and Boyer (1988) concluded that no existing psychosocial or vocational rehabilitation approach unequivocally demonstrated effectiveness in helping psychiatrically disabled persons obtain and retain competitive employment.*

*Robert Yankowitz, Ph.D.  
Susan Musante, CRC*

By the early 1980's, a consensus had developed in the psychiatric rehabilitation community that the traditional spectrum of vocational rehabilitation services had not been effective (National Institute on Handicapped Research, 1979; Skelley, 1980). Taking advantage of 1986 federal legislation which substantially reduced work disincentives for disabled people, specifically targeted people with psychiatric disabilities for transitional and supported employment, and made other improvements in psychiatric vocational rehabilitation services, practitioners began to adapt the place-train model of supported employment which had already demonstrated success with developmentally disabled people (Yankowitz, 1990). During the past decade, transitional and supported employment with job coaching and related services have proliferated, attaining widespread acceptance by psychiatric rehabilitation consumers, practitioners, and administrators and replacing the assess-train-place model as the preferred sequence of service delivery.

In addition to the sequence of psychiatric vocational rehabilitation service delivery, the nature of the services has also changed. Traditional forms of assessment such as intelligence, personality, or neuropsychological assessment are oriented primarily towards symptomatology and diagnosis, and were useful in the assess-train-place model of vocational rehabilitation. The contemporary place-train-support model, however, requires more functionally oriented assessments which focus on the individual's profile of functional competencies and deficits,

particularly as these relate to work and the work environment. While the traditional diagnostic vocational evaluation and simulated work assessment used in the assess-train-place model are function rather than symptom oriented, they are conducted in evaluation laboratories or sheltered workshops, and their outputs are therefore not based on real work environments. This reduces both their predictive validity and usefulness in guiding service delivery. Functional assessments conducted in real work settings, however, focus on disabled persons' strengths and limitations relevant to actual or likely work environments and therefore provide information more useful in the rehabilitation process than traditional methods of assessment.

## **Cognitive Deficits in Severe and Persistent Mental Illnesses**

Schizophrenia is among the most prevalent and disabling of the severe and persistent mental illnesses. Of the 1 million people in the United States with the disorder who require treatment, the large majority are unable to work (Karno & Norquist, 1989; Talbott, 1987). The rehabilitation of schizophrenia can thus serve as a generic model which illustrates the relation between cognitive deficits and effective psychiatric vocational rehabilitation.

Cognitive symptoms (delusions, thought disorders, and related speech disturbances) constitute a major portion of the clinical signs and symptoms of both the acute and chronic phases of schizophrenia (American Psychiatric Association, 1987) and historically have been recognized as a hallmark of the disorder (Bleuler, 1911; Kraepelin, 1919/1971). In addition to cognitive



symptoms, persons with schizophrenia have characteristic and pervasive cognitive deficits. These include significant impairment of attention and concentration, learning and memory, and executive skills, such as reasoning, organization, problem solving, and initiation. Persons with other severe and persistent mental illnesses (e.g., affective, anxiety, personality disorders) are similarly disabled by cognitive symptoms and deficits, although usually to a lesser extent than in schizophrenia. These cognitive deficits in turn exacerbate the occupational and social dysfunctions of people with schizophrenia (Jaeger & Douglas, 1992; Stuve, Erickson, & Spaulding, 1991). To be maximally effective, comprehensive psychiatric rehabilitation must therefore include cognitive rehabilitation (Erickson, 1988).

***During the past 10 years, however, increasing numbers of workers have joined the effort to apply cognitive rehabilitation to psychiatric populations.***

Although the pioneering work in cognitive rehabilitation was done primarily by neuropsychologists working with brain injured populations (Ben-Yishay, Gerstman, Diller, & Haas, 1970; Diller, Buxbaum, & Chiotelis, 1972; Luria, 1966, 1973; Trexler, 1981), there were some early efforts to develop cognitive rehabilitation techniques for populations with psychopathological disorders (Michenbaum & Cameron, 1973; Wagner, 1968). Despite the success of these early efforts, 15 years elapsed until sys-

tematic activity resumed to develop cognitive rehabilitation for people with severe and persistent mental illnesses (Erickson & Binder, 1986; Erickson & Burton, 1986; Spaulding, Storms, Goodrich, & Sullivan, 1986; Yozawitz, 1986). Spring and Ravdin (1992) suggested that the failure to apply cognitive rehabilitation to psychopathological disorders was due to the beliefs that psychotropic medications alone were adequate treatment, that cognitive deficits were epiphenomena<sup>1</sup> of no functional importance, and that they were not remediable. During the past 10 years, however, increasing numbers of workers have joined the effort to apply cognitive rehabilitation to psychiatric populations, and recently there has been a spate of interest in integrating this modality into the psychiatric rehabilitation process (Bellack, Mueser, Morrison, Tierney, & Podell, 1990; Green, 1993; Stuve et al., 1991). The recent increasing interest in cognitive rehabilitation by the psychiatric rehabilitation community may only have become possible now that the efficacy of other modalities (psychopharmacology, family treatments, instrumental and social skill training) has been demonstrated, and they have been integrated into comprehensive treatment. Practitioners now recognize that cognitive deficits remain even after people with severe and persistent mental illness have received adequate biopsychosocial treatments, and that these deficits impose a ceiling on the rehabilitation outcome. Thus, cognitive rehabilitation has become the latest frontier in psychiatric rehabilitation.

### **Cognitive Functional Assessment in Psychiatric Vocational Rehabilitation**

The goal of the Psychiatric Vocational Rehabilitation Program at the Mount Sinai Medical Center, New York City, is integrated competitive employment. The program consists of three sequential phases of vocational services integrated with biopsychosocial services typical in psychiatric rehabilitation. The initial assessment phase lasts 1–2

months and includes traditional diagnostic vocational assessment, situational assessment in a supervised workshop setting, and career exploration. The second phase of the program is transitional employment (TE), which includes job coaching, as necessary, and comprehensive job placement services. Participants remain in the TE phase (TEP) as long as necessary to attain readiness for competitive employment, provided they continue to improve their psychosocial or vocational performance. Assisted competitive employment is the third phase, which begins after job placement. Participants continue to receive job coaching if they choose. Some continue to attend a supportive psychotherapy group one evening a week; some attend a regular evening social club; and all continue to receive psychiatric aftercare services through the Adult Psychiatry Clinic.

The Psychiatric Vocational Rehabilitation Program uses an open screening policy, preferring to admit questionable applicants, provided that from a psychiatric viewpoint they pose no physical danger to themselves or others. By December 1992, after 5 ½ years of operation, the program had provided services to 181 people with severe and persistent mental illness. Of these, 42 were still enrolled in the program and 141 had terminated. Of the 141 people who had terminated the program, 51 (36 percent) had attained competitive employment with a 6-month job retention rate of 85 percent; four (3 percent) had entered a formal training program or college; and 86 (61 percent) had dropped out. Thirty-three (38 percent) of the dropouts had terminated the program for family or social problems, or

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**Table 1.**  
**Psychiatric Vocational Rehabilitation Program**  
**Terminations: July 1987 Through December 1992**

Psychiatric Disorders	Termination Status		
	Achieved Competitive Employment	Dropped Out Due to Psychiatric Problems	
Schizophrenia and Organic Brain Syndrome	15	26	N=41
Other Diagnoses	36	27	N=63
	N=51	N=53	
	Total N = 104		
	Chi Square = 4.35		
	p = .037		
	df = 1		

because they had decided they didn't want to work or didn't like the program. The remaining 53 (62 percent) dropouts had terminated for reasons directly related to their illness (e.g., symptom exacerbation, dysfunctionality). Many of these were referred to psychiatric day treatment or other vocational rehabilitation settings.

Of the 51 individuals who attained competitive employment and the 53 who dropped out for reasons related to illness (total N=104), 41 had schizophrenia or organic brain syndrome with associated severe cognitive deficits and 63 had other psychiatric disorders—schizoaffective {18}, depressive {18}, bipolar {14}, personality {6}, anxiety {5}, and other {2}—with generally less severe cognitive deficits. Diagnoses were not, however, distributed as expected by chance between individuals who attained competitive employment and those who dropped out. For example, while 26 individuals with schizophrenia or organic brain syndrome had dropped out, the chance

expectation would have been 21. While 36 individuals with diagnoses other than schizophrenia or organic brain syndrome attained competitive employment, the chance expectation would have been 26 (See Table 1). This disproportionality was statistically significant (chi square=4.35, p=.037 with one degree of freedom). Thus, individuals with severe cognitive deficits due to schizophrenia or organic brain syndrome were under represented in the group attaining competitive employment and over represented in the group of dropouts.

### **The Cognitive Functional Assessment Instrument**

Recognizing what appeared to be an inverse relation between participants' degree of cognitive impairment and their attainment of competitive employment, we explored further the extent to which cognitive deficits created obstacles to employment. Staff discussions confirmed that, in many cases,

participants who had trouble or failed to attain competitive employment seemed to have cognitive deficits. Furthermore, these participants' greatest work performance difficulties could be conceptualized in terms of cognitive dysfunctions. It seemed likely that cognitive deficits constituted a major obstacle for our participants which previously we had been ignoring. We therefore decided to seek additional support to develop a cognitive rehabilitation component for the program. In early 1993 we applied to the Rehabilitation Services Administration for a special project and demonstration grant to provide vocational rehabilitation services to severely disabled individuals. Our grant request was funded, and in late 1993 we hired additional staff to start the development of a cognitive assessment instrument which will be integrated into our vocational rehabilitation program. We also plan to shift the focus of treatment planning and intervention to include cognitive deficits and to develop additional cognitive rehabilitation services.

Based on the cognitive rehabilitation literature and extensive discussions with program staff who work directly with consumers and their worksite supervisors, we decided to target the six cognitive functions which seemed most frequently related to our consumers' work dysfunctions. These are: short-term attention, sustained attention (concentration), memory, flexibility, initiative, and organization. The cognitive functional assessment protocol we have developed consists of 15 items of identical format, each stating either positively or negatively a common work behavior tapping a cognitive function. Two examples appear below:

- Item 2: The TEP employee sustains attention when doing a simple task, requiring no redirection back to the task.

- Item 14: The TEP employee has difficulty starting tasks without prompting.

The answer choices are identical for all items. The respondent chooses one of four responses, each corresponding to a level of frequency with which the



behavior described in the item is typically exhibited. The answer choices are:

- Always (more than 85 percent)
- Often (51–85 percent)
- Occasionally (15–50 percent)
- Never (less than 15 percent)

There are two additional items to determine the extent to which the consumer has awareness of his or her strengths and weaknesses. The format of these items is similar to the other 15 which measure cognitive deficits.

The instrument was designed to be simple, clear, and easy to administer. It will be completed by program staff who serve as TE worksite liaisons in conjunction with the worksite supervisor who is actually familiar with the program participant's work performance. The TE liaison will read each question to the worksite supervisor, who in turn will choose the response that best describes the TE worker's behavior. A test administration handbook has been developed which contains illustrative examples for the TE liaison to read if the worksite supervisor is unclear about a question's meaning. Five examples have been developed for each item, one for each of five common TE work areas in the Med-

ical Center. The examples corresponding to items 2 and 14 are:

*Item 2:* When the TEP employee is directed to:

- insert copies of the *Hospital Newsletter* in pre-addressed envelopes,
- file a set of documents,
- log the UPS numbers on a large number of items before delivery,
- enter a long series of numbers in a database, or
- sort silverware

the TEP employee finishes the job without losing track of what he or she is doing.

*Item 14:* Although the TEP employee remembers, when asked, standing instructions like

- handing in timecards to the secretary at the end of the day,
- fetching and distributing departmental mail,
- logging in all the packages prior to delivery,
- booting up the computer in the morning, or
- washing hands and putting on gloves and hair net he or she requires prompting to start the task.

At the present time we are conducting a study of the cognitive functional assessment instrument's internal consistency, interrater, and test-retest reliability. Based on the results of this study, we will refine or replace items as necessary, adjust our administration procedures, and then begin actual clinical use of the protocol in our program.

We also have developed a consumer awareness version of the cognitive functional assessment for completion by the program participants. Discrepancies between the staff's and participants' views of the latter's cognitive deficits will be rediscussed by the participants and their rehabilitation counselors in an effort to improve participants' awareness and acceptance of their deficits. We believe that consumer awareness of the effects of their illness on their functional deficiencies is directly related to their ability to remediate their deficiencies. It is also consistent with our use of psychoeducation in re-

habilitation with people with severe and persistent mental illness.

## Using the Cognitive Functional Assessment Protocol Throughout the Psychiatric Vocational Rehabilitation Process

The new cognitive functional assessment will be added to the program's existing functional work assessment, which consists of 20 behavioral questions addressing attendance, punctuality, interpersonal relationships, and work behaviors, including attitudes, skills, and stamina.

The first administration is 1 month after a consumer starts the program, while he or she is still in the initial assessment phase. The combined assessment protocol is administered periodically by program staff as follows:

- The participant's rehabilitation counselor completes the protocol based on discussion with the workshop supervisor. After the participant completes the consumer version of the protocol, both the participant and his or her rehabilitation counselor meet for a "progress review" to discuss the results of the protocols as completed by both staff and participant. The discussion focuses on identifying principal strengths and weaknesses and incorporating recognition of these into a general plan for corrective action and skill enhancement in the work setting.

- The treatment plan is modified as necessary with the participant's involvement and approval, and appropriate staff are informed of the new plan.

The second combined cognitive functional and work assessment protocol is completed 6 weeks after the participant is placed on a TE worksite. This time, the procedure is as follows:

- The participant's rehabilitation counselor completes the protocol based on discussion with the TE worksite supervisor.

- The participant again completes the consumer version of the cognitive functional assessment.

***We also have developed a consumer awareness version of the cognitive functional assessment for completion by the program participants.***



- As before, the participant and his or her rehabilitation counselor then meet for a progress review, during which they revise the treatment plan to incorporate outputs from the assessment protocol.

- The counselor consults with the staff cognitive rehabilitation specialist to develop a service plan which includes the necessary compensatory strategies, environmental modifications, and employer awareness interventions specific to the TE worksite based on the assessment protocol outputs. The cognitive rehabilitation specialist initiates the implementation of this plan, and supervises the job coach to continue implementation of the plan by working intensively with the participant on the worksite.


The cycle of functional assessment, progress review, treatment plan revision, and cognitive rehabilitation service implementation is repeated every 3 months while the participant is on the TE worksite. Some of these services may continue as necessary after the participant attains competitive employment, provided he or she is wants them. They then become part of the follow-along support services provided during the assisted competitive employment phase of the program.

### Further Enhancements of the Psychiatric Vocational Rehabilitation Program

We expect that as program participants and staff become more aware of the pervasiveness and influence of cognitive deficits on participants' behavior, the focus of program activities will increasingly shift to include more emphasis on cognitive deficits and activities and interventions intended to ameliorate them. Development and continuous use of the functional cognitive assessment protocol and its outputs constitute the first structured push in this direction. This will be followed by the delivery of individualized cognitive rehabilitation services at the worksite. In addition, we have begun to develop cognitive rehabilitation group

activities to be delivered on a regularly scheduled basis on the program premises by the program psychologist and cognitive rehabilitation specialist. In addition to small group (four to eight participants) activities designed to remediate deficits in specific cognitive functions (attention, memory, flexibility), we plan to start a group to promote participant awareness of their cognitive deficits. We believe that this awareness is crucial to participants' ability to utilize the program to achieve their goals.

### Summary

These are exciting times to be working in psychiatric vocational rehabilitation. The biopsychosocial innovations developed and refined during the past 30 years are now commonplace. The supported employment techniques more recently developed are also practiced widely, and their benefits to consumers are apparent. Cognitive rehabilitation is the latest innovation to be grafted into psychiatric rehabilitation programs. Although its potential is promising, it is not a panacea. There are years of hard work ahead before we can routinely and systematically use cognitive rehabilitation in assisting our consumers to reach their highest level of independent community functioning. We would all be well-advised to temper our expectations with healthy realism as we proceed with our work. 

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### Notes

1. Secondary phenomena overlapping and resulting from another.

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*mental disorders/III, revised*. Washington, DC: American Psychiatric Association.

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## Museum Featuring Artifacts for Blind and Visually Impaired Opens

The Museum of the American Printing House for the Blind (APH) opened October 12, 1994, with a public reception. Located at 1839 Frankfort Avenue in Louisville, Kentucky, the museum exhibits artifacts relating to the history of the education of people who are blind and visually impaired. Products and machinery from APH, founded in 1858, are the focus of the collection.

This museum serves as the only national depository for relics used by blind people to communicate and interact in a sighted world. The purpose of these unique exhibits is to increase public understanding of how visually impaired people achieve independence.

Embossed books, tactile maps and globes, and early mechanical braille writers are displayed with corresponding photographs illustrating the pioneering activities of APH. Helen Keller's braille Bible, which was printed here, is one illustration of the fascinating objects that this museum makes available to the public.

The APH Museum is accessible to visually and physically impaired visitors and contains interactive and hands-on exhibits and stations for audio description. Admission is free and the museum is open to group tours. Regular hours are 8:30 a.m. to 4:30 p.m., Monday through Friday.

The APH Museum received financial support from the J. Graham Brown Foundation; J.J.B. Hilliard and W.L. Lyons, Inc.; the Mary and Barry Bingham, Sr., Fund; and the Kentucky Humanities Council.



# Survivor Training and Empowerment Program (S.T.E.P.)

***On Sept. 30, 1992, the Rehabilitation Services Administration (RSA), awarded the Colorado Department of Social Services (now called the Colorado Department of Human Services), Rehabilitation Services (now called the Division of Vocational Rehabilitation), a 1-year renewable \$108,178 grant to develop and implement the Survivor Training and Empowerment Project (S.T.E.P.) described in this article. The grant, in the fourth quarter of its second year of operation, is administered by the Rocky Mountain Regional Brain Injury Center (RMRBIC), which was established in 1990 through grant funds from RSA.***

*Pat Breese, M.A.  
Sharon Mikrut, M.S.W.*

Survivors of traumatic brain injury (TBI) and their families face an extremely complex and potentially confusing array of services, medical professionals, and human service delivery systems. The course of rehabilitation is extensive, sometimes encompassing many years, numerous medical disciplines, social service delivery systems, and bureaucratic entities. The process of rehabilitation and community reintegration following brain injury often requires years of effort and major medical and rehabilitative expenses. Survivors of TBI emerge from the medical milieu concerned about the future but unaware and unformed of the bureaucratic and medico-legal challenges that lie ahead.

Most survivors of TBI receive time-limited case management services through the insurance carrier responsible for covering the accident or through a facility-based case manager who acts as an internal coordinator of the rehabilitation team. However, once the injured person leaves the facility and insurance monies are depleted, case management (service coordination) either stops or is abruptly transferred to the family. Therefore, upon transfer to the home or community, families, by default, begin to face the reality of providing long-term support and service coordination with limited financial and emotional resources.

Survivors, through extensive hospitalizations and indoctrination into the role of the patient, frequently learn to passively accept medical treatment and rehabilitation options available to them. After discharge from the medical set-

ting, they are thrust into the role of fending for themselves with few supports and are often unable to obtain information on existing services or programs which address their unique needs.

Unfortunately, little preparation is given to people with brain injury and their families to adequately function in their new role as "service coordinator." Forced to fill the role of self-advocate or service coordinator, survivors and their families learn about available services and procurement of those services in a lengthy piecemeal process that may never reveal the full spectrum of assistance available. The process is a time-consuming, frustrating, and potentially overwhelming endeavor for a family already taxed by the advent of a traumatic event.

Human service delivery systems and state social service systems, which typically assume responsibility for the provision of long-term support and case management, are unable to keep pace with the ever increasing demand for services to a population of Americans who live longer and have more severely disabling conditions. Case management—or service coordination—specifically for people with brain injury has not been developed in most states and is not readily available to these individuals who have difficulty accessing other social service systems. As a result, many survivors of brain injury "fall through the bureaucratic cracks," are unable to access services available to people with other disabilities, and become exhausted by running the gauntlet of social services before they realize any success for their efforts. The solution to provision of service coordination to people with brain injury relies on two complementary approaches:



- the creation of long-range service coordination or case management through formal systems and
- instruction of individuals in self-advocacy skills to enable them to independently accomplish as much as possible.

Early intervention is critical in setting a course for successful long-term planning and the smooth transition between phases of rehabilitation and community reintegration. Due to the effects of protracted stress in providing for all of the needs of their survivor with little or no assistance from support systems, families may dissolve or develop secondary psychosocial issues. People with brain injury may also develop secondary emotional or substance abuse problems, compounding an already debilitating injury. These secondary disabling conditions, which occur primarily as a result of frustration, isolation, and society's inability to support survivors of TBI, make the return to maximum independence and productive activity more problematic than necessary. Early involvement with a skilled support person who will help bridge gaps in service and assist in accessing needed services helps to reduce the frustration of continually being denied service and lessens the likelihood of secondary disabilities frequently observed with TBI.

Vocational counselors are aware of the impact of psychosocial disturbances and lengthy unemployment on individual vocational performance and competency. Statistics favor early vocational intervention for individuals with TBI and emphasize the positive effects of rapid return to work. Expedient return to productive activity mitigates the feelings of powerlessness and uselessness frequently occurring after a debilitating illness or injury and maintains the individual's vocational motivation and confidence. Provision of survivor-directed service coordination supports the efforts of vocational rehabilitation (VR) with early intervention and stabilization of a psychosocial function, thus easing the burden of responsibility on VR counselors to provide case management services and deal with secondary disability. VR



*TBI survivor Sue Witherspoon, peer service coordinator, El Paso County.*

counselors often do not have sufficient time to act as both full spectrum case manager and vocational specialist.

Two coordinators who have personally experienced the effects of brain injury were hired to serve under this project. Having a disability similar to those you serve can facilitate the understanding of and adaptation to the disability, and the value of peer counseling has been demonstrated in many other areas of rehabilitation and mental health as well as independent living centers. S.T.E.P. envisions the applica-

tion of this approach to the direct provision of service coordination for people with brain injury by people with brain injury.

This project seeks to demonstrate the utility of survivor-directed service co-

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*Ms. Breese is Program Coordinator for the Colorado Brain Injury Medicaid Waiver Program and Ms. Mikrut is Executive Director of the Rocky Mountain Regional Brain Injury Center, Denver, Colorado.*





*TBI survivor Evelyn Logan, peer service coordinator, Mesa County*

ordination and self-advocacy training for people with brain injury, as private systems are limited in scope and public systems are either inadequate or nonexistent. Philosophically aligned with current consumer empowerment approaches and responsive to the need for comprehensive service coordination, S.T.E.P. contains two significant components: early intervention service coordination for and training and development of advocacy skills among the recipients of service coordination,

thus enabling consumers to gradually assume greater degrees of independence and responsibility.

Survivors of moderate to severe TBI living in the Colorado counties of El Paso and Mesa are the target population for services under this project. These two counties were selected due to their ongoing TBI surveillance projects which allow for the concise collection of data on incidence, outcome, and costs for TBI during the first 18 months post injury. El Paso County, an urban area

which includes the city of Colorado Springs, reported 418 cases of head injury, with 338 survivors, in 1988. For the same year, Mesa County, a rural area served by the urban center of Grand Junction, reported 100 cases of head injury, with 66 survivors.

Another goal of the project is to compare costs/experience in the first year post injury for individuals tracked by the surveillance project in El Paso county who receive no case management services with those who receive service coordination under S.T.E.P. At the end of the grant period, the service coordinators will bridge an existing gap in the provision of service coordination among acute care, post acute care, community reintegration, and return to productive activity for 108 people in the two-county area.

S.T.E.P.'s service coordinators may also provide outreach to survivors—located through contacts with service agencies, local head injury support groups, long-term care facilities and independent living centers—who are several years into the community reintegration phase of their rehabilitation process. In these situations, the focus of the service coordinator is primarily information provision and referral to resources and self-advocacy training rather than intensive service coordination.

### **Early Intervention Service Coordination**

S.T.E.P. service coordinators begin working with survivors and their families while they are still hospitalized in acute rehabilitation facilities by participating in staffing and family educational sessions to familiarize themselves and to begin building rapport with the injured individuals, their families, and the rehabilitation team. Both coordinators had offices in acute rehabilitation facilities where they were linked directly with professional staff who reviewed cases with them. Although they are now located in State Division of Rehabilitation offices, they continue to work with professionals from acute rehabilitation facilities in a variety of ways and serve in the dual role of co-



ordinator/advocate and mentor to assure recovery from the devastating effects of TBI.

At this stage, the service coordinators will assess each potential client to determine if he/she is eligible for participation in the S.T.E.P. program, as determined by the following criteria:

1. The person must have sustained a documentable moderate to severe TBI which is described as:

- an insult to the brain that may produce a diminished or altered state of consciousness, resulting in impairment of cognitive abilities or physical function or in the disturbance of behavioral or emotional functioning (these impairments may be either temporary or permanent and cause partial or total functional disability or psychological maladjustment);

- a loss of consciousness greater than 30 minutes has occurred;

- a loss of memory for events immediately before or after the accident has occurred with post traumatic amnesia lasting for more than 24 hours;

- an alteration in mental state; or
- an initial Glasgow Coma scale measurement of 13 or less.

2. The individual must reside in El Paso or Mesa County, or one of the adjacent counties.

3. The person with the injury and/or their family must desire the services of the peer service coordinator and have made an informed consent to participate.

After the above criteria have been met, an initial meeting is arranged at a mutually convenient time and place. With the permission of the survivor, family members or others interested may participate in meetings. An assessment form, the *Functional Outcome Rating Scale* (FORS), is used to guide the initial determination of the current level of functioning on a scale of one to five in seven areas of emphasis: Medical; Cognition/Behavior/Emotions; Communication; Mobility; Self-Care; Leisure Time/Recreation/Social; and Vocational/Educational. The need for information and additional supports to enhance function and independence is based upon information obtained through this process. The assessment

form includes an open-ended section which provides an opportunity for individuals with brain injury to state personal goals in each of the seven areas. FORS is utilized as a baseline of information to measure progress, as a blueprint for cooperative development of the initial service coordination plan, and as a tool for feedback to encourage the participant to monitor his/her own progress.

*From the initial assessment interview the service coordinator determines which community resources can best accomplish the agreed upon goals.*

From the initial assessment interview the service coordinator determines which community resources can best accomplish the agreed upon goals. If necessary services do not exist within a reasonable distance, the service coordinators become advocates for the development of community-based services and may negotiate arrangements with potential providers of service. Throughout this process of information, referral, advocacy, and monitoring, service coordinators take an instructive role in providing information and teaching advocacy skills, while simultaneously providing ongoing service coordination. Maximum emphasis is placed on the least restrictive environment and highest degree of personal choice.

### **Self-Advocacy Training**

The project provides a model and curriculum prepared by and for sur-

vivors of TBI to promote self-advocacy. This model is used to directly train people with brain injury and their families and is disseminated directly to survivors, their families, and service providers in the states of Colorado, Montana, New Mexico, North Dakota, South Dakota, Utah, and Wyoming. Because the project teaches survivors to manage their own recovery process and subsequent community reintegration, it decreases demands on existing service delivery systems for resources and personnel. The survivors, for the most part, move into and out of the project, thus making room for more survivors to be served. Those individuals who do require ongoing or even lifelong service are enabled to manage more components of their own lives, again reducing the drain on the service coordinator and other social service systems.

Each coordinator works individually with families and survivors in a paced application format of the *Self-Advocacy for Independent Living* (S.A.I.L.) program, covering topics as they become germane to the individual's life. The service coordinators utilize the S.A.I.L. workbook developed by the Colorado Head Injury Foundation and each recipient of service coordination is provided with a complete S.A.I.L. workbook. In addition, each coordinator assists in the sponsorship and organization of local ongoing S.A.I.L. training workshops for survivors and family members who desire additional training and support. Through a separate project funded by RMRBIC, interested coordinators in the seven-state region are developing a S.A.I.L. training program which will interface with the S.T.E.P. service coordinators in promulgating the self-advocacy model across the region during the second half of the project.

Self-advocacy training is expected to teach skills to the newly injured and their families to enable them to:

- control the type and source of treatment received;

- be free to refuse treatment and/or service;

- have access to all relevant information about their own treatment;



- comprehend the process of appealing any decisions which affect them;
- make informed choices;
- rely on service providers to be catalysts and resources rather than decision makers;
- take reasonable risks and have the right to fail but to take responsibility for change;
- acquire skills that will maximize their independence as they define it; and
- engage in productive activity commensurate with their needs, abilities, and interests.

**One of the expected benefits of the self-advocacy training is enhanced utilization of state VR services.**

One of the expected benefits of the self-advocacy training is enhanced utilization of state VR services. Historically, state VR counselors have regarded survivors of TBI as a population which requires more counselor time than other disability groups. Survivors trained in self-advocacy should need far less case management services from the VR counselor, freeing the counselor to concentrate on vocational issues. It is likely that counselors will have a more positive attitude toward serving survivors of TBI if they know that they will not have to spend limited resources of time and money on case management services.

### **Training of the Service Coordinators**

Acknowledging that people with brain injury may need adapted learning methods and pacing, a multifaceted training format was designed with maximum emphasis on "hands on" experience in the mastery of new information. The training curriculum allows for a *gradual* acquisition of infor-

mation and skills through formal instruction, internships, and ongoing supervision. Practical application in the internships and through working with clients in supervised settings reinforces material provided in written format and provides an opportunity to apply abstract ideas.

### **Introductory Training**

With input from RMRBIC staff and the Survivor's Council, a 3-week training curriculum was developed that included topics such as *Confidentiality, Documentation, Professional Ethics, Orientation to Vocational Rehabilitation, Orientation to RMRBIC, Policy and Procedures, Budget Management, Stress Management, Counseling Techniques, Family Dynamics, Substance Abuse Issues, Case Management, Community Resource Development, Insurance Issues, SSDI and SSI, Other Financial Resources, and Medical and Rehabilitation Continuum.*

### **Internships**

The utilization of internship sites provided the opportunity for service coordinators to take a hands on approach to the acquisition of information from complex systems like social services and Social Security. Each peer service coordinator completed internships within the county in which they would be serving clients, thereby allowing time and the occasion to develop personal contacts with key personnel within specific service delivery systems.

Internship sites were arranged and negotiated with the following entities: county departments of social services, rehabilitation hospitals (inpatient, outpatient, day treatment, nursing services, physical therapy, occupational therapy, speech therapy, psychological services, and substance abuse consultants), independent living centers, Social Security, and state VR. The length of internships varied from 2 days to 6 weeks, depending on the intricacy of systems involved, relevance of the material to the service coordinator's role, and availability/willingness of professionals to provide train-

ing and supervision. In addition, the interns were provided with a listing of expected competencies on which to focus their attention on pertinent topics within each internship site. These competencies ranged from general interpersonal skill development to specific clinical skills of case management or service coordination. The sites were also provided with a copy of these competencies to enable them to tailor the training to the needs of the peer service coordinators. All internship sites that lasted beyond 2 days (all but one) completed a structured evaluation of the service coordinators. Supervision was provided by RMRBIC's case manager and onsite supervisors. The two peer service coordinators completed training within 9 months of the original grant start date.

### **Self-Advocacy for Independent Living Training (S.A.I.L.)**

As discussed earlier, S.A.I.L. functioned as a component of the S.T.E.P. advocacy training program for participants and was also employed to train the peer service coordinators in April 1993 through a 2-day workshop sponsored by the Colorado Head Injury Foundation. Further instruction was provided in August 1993 and refresher courses are offered annually to assist the coordinators in trouble shooting areas of difficulty and to review areas of concern or project weaknesses.

### **Ongoing Training Opportunities**

Both peer service coordinators have participated in a variety of additional conferences and training sessions throughout the initial 18 months, including housing conferences, brain injury rehabilitation seminars, victim's assistance training, and interpersonal skill training.

### **Advisory Bodies**

The grant has two primary advisory bodies: the *Survivor's Council* and the *Service Providers Advisory Board*. The Survivor's Council, which usually



meets bimonthly, is comprised of six persons with brain injury who provide guidance to the peer service coordinators and project director in determining the training needs, methods for provision of services, and methods of reaching potential beneficiaries and serve as an appeals board in the event of any dissatisfaction by recipients of S.T.E.P. The Service Providers Advisory Board, which consists of six members, provides input regarding participant selection criteria, outcomes measurement, internal evaluation research design and other matters of technical support. This board is comprised of representatives from the state VR offices, Colorado Department of Health, and Craig Hospital Research Department and meets four times per year via teleconference but provides ongoing technical assistance whenever necessary.

## Evaluation/Research Component

The S.T.E.P. project contains both an internal and external evaluation component. The internal evaluation is monitored by the Survivor's Council, the Service Providers Advisory Board, and the project director and measures variables such as the numbers of clients served, types of services provided, documentation, number of clients returning to work, development of self-advocacy skills in clients, and level of independence attained. The external evaluation is comprised of three separate facets: customer satisfaction surveys, referral source satisfaction surveys, and cost-benefit analysis, which will weigh the cost of intensive service coordination against the long-range benefit of durable improvements in increased levels of independence and productive endeavors. Funding has been allocated for a doctoral level student to consult with the project and complete followup data collection of the project's participants. Data on the outcome and cost-benefit analysis of the grant will be available before the S.T.E.P. grant expires on September 30, 1995.

## Issues to Consider Should the Project be Replicated


Several problems arose in the initial phases of project implementation; these issues were primarily centered around an overly ambitious implementation schedule. Initial training for the peer service coordinators was completed in 6 months but absorbed more time than originally allotted for this process. It was imperative, given the nature of TBI, that these coordinators be given adequate time to digest and integrate new job-related information and feel equipped to enter their positions with confidence. The transition to full-time employment combined with relocation to new communities proved to be too stressful for a smooth transition in the 6 month allotted time. To ameliorate some of the difficulties and stresses of the new job, both coordinators were provided with a variety of supportive services, from employee assistance counseling to job coaching. In retrospect, the implementation schedule did not allow for adequate time to transition or train the service coordinators, both of whom had limited mental and physical endurance. Ideally, the training component for a program of this nature should be extended over a year and maintain a flexible approach which could be easily modified if necessary.

A second area of related stress for the peer service coordinators came in the relocation to new communities, which necessitated a total disruption of lifestyle and support systems. It was the intent of the authors of the project to hire coordinators from the El Paso and Mesa County areas; however, this did not prove possible and the resulting change for the new employees was much more dramatic than originally anticipated. Should this project be replicated, every effort should be made to mitigate the simultaneous changes required of persons with brain injury who become employed as peer service coordinators.

Another problem area has been the eligibility criteria for the project's participants, which originally included re-

strictions on the admission of people who had evidence of previous or ongoing substance abuse issues. After extensive discussion with the Survivor's Council and Service Providers Advisory Board, consensus was reached regarding which criteria were necessary for the purity of research design and which criteria best served the needs of the population. Overly restrictive criteria limits the pool of available participants. Care must be exercised in determining the selection criteria to adequately adhere to research design and protocol without limiting options for serving people who are in need.

Next, initial marketing of the new program to potential referral sources consumed additional time and was also not included in the original project implementation timeline. Marketing to potential referral sources did not start in earnest until the service coordinators were trained and out in the field. Both coordinators expended considerable effort in contacting and making presentations to hospital personnel, social service systems, and allied mental health workers and working with those people with whom they had become familiar as a result of the internship experience. Additional manpower should be considered prior to replicating this project.

Finally, allocating 15 percent of the project coordinator's time to provide supervisory oversight, training development, and initial program development was a gross underestimation of the amount of time actually required to begin a program of this nature. In the second year of the grant, 30 percent of the project coordinator's time is allocated; however, this is probably still inadequate. The S.T.E.P. peer service coordinators commented frequently on their desire for more direct and frequent supervision and often stated they felt "out there alone" dealing with very challenging situations; they desperately needed to feel that assistance was readily available if needed. Adequate supervisory oversight and/or the provision of a direct mentor should be considered as options to providing supervision at a distance, should this project be replicated. 



# Peña Points to DOT Progress Toward Accessible Transportation

**M**arking the fourth anniversary of the signing of the Americans With Disabilities Act (ADA), U.S. Secretary of Transportation Federico Peña said the department has made substantial progress toward a national transportation system that is accessible to travelers with disabilities.

In the first meeting any Transportation Secretary has ever initiated with major leaders of the disability community, Secretary Peña said, "We know transportation is the key that allows people with disabilities to enter the mainstream. The department has been working vigorously to carry out the requirements of the ADA, and we can point to many accomplishments.

"However," he added, "the task is far from complete. There are some regulations not yet in effect, and other rules that need to be put in place to remove barriers."

The department also is including people with disabilities in its extensive efforts to develop the recently announced National Transportation System, which embraces all forms of transportation—highways, waterways, transit systems, pipelines, airports, seaports, and rail lines, both passenger and freight.

Here is a status report on transportation accessibility.

**Mass Transit:** Every federally aided mass transit system provides some type of accessible service for passengers with disabilities. Accessibility improvements such as bus lifts and vehicle ramps are appearing rapidly, as well as door-to-door paratransit (alternate services) vans for people who cannot use the fixed routes. Transit rail systems are upgrading their key stations—transfer points or those that are heavily used—and buying new rail cars with accessibility devices. The department provides information and technical assistance to the transit industry on making vehicles and stations accessible and has established the National Transit Institute at Rutgers University to educate transit operators on all key aspects of ADA.

**Railroads:** Regulations for Amtrak as well as transit systems call for one car per train to be accessible by 1995. Existing Amtrak stations must be modified by the year 2010. Amtrak operates a customer service desk that assisted more than 150,000 senior citizens and passengers with disabilities in 1993.

**Aviation:** It is now much easier for most travelers with disabilities to use the air transportation system. Required accessibility features (at airports and carrier terminals that receive federal aid) include parking, baggage services, in-

formative signs, water fountains, bathrooms, ticket counters, and information/telecommunication devices. In addition, airline policies may not impose unnecessary burdens on air travelers with disabilities, such as requiring a companion to serve as a personal attendant.

U.S. airlines are required to install special features on new and refurbished aircraft. The department estimates that by the end of 1993, 10–20 percent of the fleet, or 400–800 aircraft (with more than 29 seats) had movable armrests on half of the aisle seats. Nearly all new and existing aircraft have onboard wheelchairs for cabin use. About 200 planes (with more than 99 seats) provide cabin stow space for at least one folding wheelchair, and roughly 10 percent of twin aisle aircraft have fully accessible lavatories. A rule requiring accessible boarding equipment for commuter aircraft (19–30 seats) will be issued in the near future.

**Highways and Streets:** Nearly all rest areas on Interstate highways and other new roads funded with federal aid are now accessible. Streets and highway pedestrian facilities being constructed, renovated and altered with federal aid are being brought into conformance with regulations that require installation of curb cuts to accommodate wheelchairs.

**Intercity Buses:** The department is currently developing proposals to establish accessibility requirements for intercity, charter and other over-the-road bus services. The rule would take effect by the ADA deadlines of 1996 and 1997.

**Maritime:** DOT is conducting research to help develop accessibility standards for maritime vessels and facilities, ranging from ferry boats to cruise ships.

According to DOT, people with disabilities played a major role in drafting and commenting on DOT's transit and air accessibility regulations and the department continues to seek their guidance on new ADA rules. Meeting with the Secretary were representatives of the National Council on Independent Living, American Council of the Blind, American Federation of the Blind, Paralyzed Veterans of America; Eastern Paralyzed Veterans of America, National Association of the Deaf, National Association of Protection and Advocacy, Center for Independent Living (Berkeley, California), Disability Rights Education Defense Fund, and Independence Center of Northern Virginia.

The department also provides \$2 million in annual funding to Project ACTION, operated by the National Easter Seal Society, which brings together all key decision makers in implementing ADA.



# NEW PUBLICATIONS AND FILMS

## **Business As Usual. A new video on creating economic opportunities for people with disabilities.**

Sherry Kozak. *Fanlight Productions*, 47 Halifax Street, Boston, MA 02130. 39-minute video. \$195, purchase; \$50 per day rental.

This documentary attempts to bring a unique international perspective to the struggle for equality in society and the workplace for people with disabilities; it examines five innovative programs which create opportunities for people with mental and physical disabilities to own and operate their own businesses. In Jamaica, Canada, Kenya, and the Philippines, we visit people with physical and mental disabilities who have created—and who now own and operate—successful, profitable businesses which provide employment, income and self-reliance for themselves, their families, and employees.

## **When Billy Broke His Head... And Other Tales of Wonder.**

Billy Golfus and David E. Simpson. *Fanlight Productions*, 47 Halifax Street, Boston, MA 02130. 57-minute video. \$245, purchase; \$50 per day rental.

When Billy Golfus, an award-winning radio journalist was brain damaged as a result of a motor scooter accident 10 years ago, he became one of the 43 million Americans with disabilities—this country's largest and most invisible minority. He struggled with his own rehabilitation and came home from the hospital, only to discover that physical rehabilitation was only the first battle he'd have to fight. In America, disability is not just a medical fact, it is also a political reality. In this irreverent, first-person road movie, Golfus, a sort of underground Charles Kuralt, goes on the road to meet people with disabilities

around the country and witness firsthand the strength and anger that is forging a new civil rights movement.

This video blends humor with politics and individual experience with a chorus of voices to explore what it is really like to live with a disability in America—where pervasive discrimination and bureaucratic “helping” systems too often keep people with disabilities trapped in a labyrinth of government rules and legislated poverty. As Billy says, “This ain't exactly your inspirational cripple story.” It's a documentary with an attitude, which should entertain, enlighten, and might even enrage it's viewers.

## **New Solutions to Old Problems: Telecommunications for Deaf and Hard-of-Hearing Employees.**

Diane Castle. *Rochester Institute of Technology (RIT), National Technical Institute for the Deaf (NTID), Campus Connections Bookstore*, 48 Lomb Memorial Drive, Rochester, NY 14623-5604. Telephone: (716) 475-2504 (voice), 475-7071 (TTY). \$2.

This booklet offers a current, comprehensive, and practical overview of telecommunication options for deaf and hard-of-hearing employees.

“In recent years, telecommunication options have expanded tremendously beyond the standard voice phone and even the standard text telephone (TTY),” reports the author, Dr. Diane Castle, audiology professor at NTID, a college of Rochester Institute of Technology. “Such changes have enabled deaf, hard-of-hearing, and hearing employees and customers to communicate with one another.”

This booklet describes creative uses of rapidly changing technologies in visual telecommunications that can be crucial

for deaf employees and helpful to some hard-of-hearing employees. It also includes information about federal legislation that focuses on telecommunications as well as other areas of access.

NTID, one of RIT's eight colleges, is the world's largest technological college for deaf students. Created by Congress, NTID represents the world's first effort to educate large numbers of deaf students within a college campus planned primarily for hearing students. Among RIT's 13,000 full- and part-time students are nearly 1,100 deaf students from the United States and other countries who study and reside on the RIT campus.

## **Leadership and Technology Management (LTM).**

*Center on Disabilities, California State University, Northridge (CSUN), July 1, 1994. 14-minute videotape. Free.*

This captioned videotape describes CSUN's new training program, a joint venture of CSUN's Center on Disabilities and the California State Department of Rehabilitation, under a grant from the National Institute on Disability and Rehabilitation Research (NIDRR), U. S. Department of Education.

Designed to give an overview of CSUN's new 5-day training program under the California State Tech Act grant, the tape offers the viewer a taste of the main themes of systems change and consumerism.

For a free copy of the videotape and/or additional information, contact: Gene Rodgers, CSUN Coordinator, State Tech Act Grant Center on Disabilities, California State University, Northridge (CSUN), 18111 Nordhoff St., Northridge, CA 91330-8340. Telephone: (818) 885-2578. FAX: (818) 885-4929.



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# AMERICAN Winter 1994-95 REHABILITATION

## Severe Mental Illness

Part 1 of 2





# RSA's Commitment to Services for Persons with Severe Mental Illness

(Part I)

**T**he National Institute of Mental Health estimates that there are between 4 and 5 million people in the United States who have severe and persistent mental illness. Approximately 1.4 million adults of working age reported through the National Health Interview Survey in 1989 that they were unable to work or were limited in work because of the effects of these illnesses. Other studies place the unemployment rate at 70 to 90 percent for persons with severe and persistent mental illness.

Despite these formidable figures, many people who have severe and persistent mental illness have a strong desire to work. The opportunity to perform real work that suits a person's talents and abilities is critical to the development of self-identity and self-reliance for all people, perhaps even more so for those who have severe and persistent mental illness.

Recent developments in a variety of areas have converged to provide a hopeful outlook on employment opportunities for this population. For many, newer medications have resulted in dramatic reduction of symptoms. People benefiting from these medications are able to realize their dreams for employment and for greater involvement in their communities. Rehabilitation experience and research of the past two decades has imparted a philosophy that people with severe disabilities, including mental illness, can work when the strengths of the person are acknowledged, when individualized services are provided, and when appropriate supports are used to accommodate and compensate for the individual's functional limitations. This philosophy is the cornerstone of the Americans with Disabilities Act and the Rehabilitation Act of 1973, as amended. Both pieces of legislation also call for greater involvement of individuals with disabilities in overall policy and program development and in the development of their own individualized accommodations and rehabilitation programs.

Despite these advances, much is not known about how specific vocational interventions and



*Commissioner Fredric K. Schroeder*

combinations of interventions interact with each person's unique characteristics and desires and with services available within the larger community, and much of what is known is not always disseminated widely.

To assist in dissemination efforts, the Rehabilitation Services Administration decided to devote an issue of *American Rehabilitation* (AR) to the topic of Severe Mental Illness. Responses to a request for articles for such an issue generated enough material for two issues. It is my pleasure to introduce the Winter issue of *American Rehabilitation*, the first of two consecutive issues on the topic of Severe Mental Illness. It is my hope that sharing the knowledge included in these two issues will help researchers, service providers, and consumers to advance the goal of employment opportunities for all people who have severe and persistent mental illness and who want to work.



# AMERICAN REHABILITATION

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Cover Photo: Pride on a first job translates into dignity for an employee who went on to work in this grocery chain in her own neighborhood after training and job placement received at the Thresholds psychosocial rehabilitation program in Chicago (Photo by Bruce Powell).

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# Recent Trends in Vocational Rehabilitation for People with Psychiatric Disability

Judith A. Cook, Ph.D.  
Susan A. Pickett, Ph.D.

Current developments in vocational services for people with mental illness suggest a shift from viewing this disability as the "last frontier" for the field of rehabilitation (Ruffner, 1986, p. 35) to a more normalized perspective recognizing the untapped employment potential of persons with mental illness. Acknowledging that unique features of psychiatric disorders require specialized service delivery approaches (Cook, Jonikas, & Solomon, 1992), recent program development and model testing offer new information about how best to assist aspiring workers with psychiatric disabilities. To complement this vocational trend, a small wave of supported education efforts has shown the effectiveness of postsecondary education for career advancement (Unger, 1994). Legislatively, the impact of the Americans with Disabilities Act (ADA) on em-

ployment outcomes for people with mental illness has the potential to be far-reaching and profound (Solomon, 1993). The consumer/psychiatric survivor movement and growth of consumer run businesses and vocational services have added to the development of this field. These and other forces are described in what follows, concluding with a look toward the future as the field nears the end of the 20th century.

## New Directions in Psychiatric Vocational Rehabilitation

An overview of recently published research and program descriptions suggests a number of areas of development in employment services for people with psychiatric disabilities. These include: how best to conduct vocational assessments given psychiatric symptoms and potential cognitive impairments; linkages between psychiatric symptoms, diagnosis, and employment success; the effects of employment on

workers' self-esteem, job satisfaction, and morale; ways employers and coworkers treat workers with mental illness, especially around ADA issues such as reasonable accommodations; new vocational models emphasizing individualized approaches and ongoing job supports; the development of consumer-run businesses and other consumer-provided vocational services; and, finally, the tailoring of vocational service models for special populations, such as women, ethnic minorities, and youth with mental illness.

*Vocational assessment.* There is general recognition that vocational assessment for persons with mental illness may be complicated by medication side-effects, psychiatric symptoms, and cognitive impairments that may occur with these disorders. Moreover, persons with psychiatric disability are known to perform differently in different environments, supporting the need for situation-specific assessments. Complicating the picture somewhat is the fact that many vocational assessment procedures were designed for those with physical disabilities or mental retardation.

The use of computerized work sampling batteries might be expected to surmount many of these problems, given their emphasis on assessing actual skills in multiple domains. Work sampling batteries contain tests of a number different dimensions, such as visual-spatial ability, motor skills, social skills, and intelligence. Yet recent studies of one such battery—the *McCarron-Dial*—confirm earlier research (Fortune & Eldredge, 1982) suggesting that its predictive validity is weak among persons with psychiatric disabilities (Cook & Razzano, 1994). In addition, female clients with mental illness scored sig-

***This article reviews recent developments in psychiatric vocational rehabilitation program design and evaluation research. Topics addressed include: new directions in vocational assessment; the link between psychiatric symptoms and employment; effects of work on self-esteem and life satisfaction; employer and coworker relationships; new vocational service delivery approaches; the development of consumer-provided vocational services; and tailoring of services for women, minorities, and youth. Implications for the future direction of the field are also discussed.***



nificantly lower than their male counterparts on this battery (Razzano & Cook, 1994) even though their eventual employment outcomes (employment status and hourly salary at both 6 and 12 months post-testing) were not significantly poorer, as had been predicted by their test results. Since this battery is composed of subtests that have documented race and gender biases (Razzano & Cook, 1994), this increases the likelihood that its predictions will be significantly biased as well.

Other evidence suggests that situational assessment may provide the most useful, valid, and reliable method of vocational assessment for people with psychiatric disabilities (Rogers, Sciarappa, & Anthony, 1991). Situational assessment is the longitudinal observation and rating of job behaviors and attitudes in actual or simulated work settings (Cook, Bond, Hoffschmidt, Jonas, Razzano, & Weakland, 1991). Use of situational assessment in tandem with other methods may offer greater accuracy while broadening our knowledge about assessments helpful to clients themselves in making their own decisions about goals and desired services (Bond & Dietzen, 1993). Another suggestion is to use situational assessment to further explore areas that *do* have a demonstrated link to employment outcomes, such as social skills and motor abilities (Razzano & Cook, 1994). Multiple assessment methods can target areas of strengths and weaknesses, pointing rehabilitation professionals to services that are tailored to the particular job and client. To assist in this effort, a manual has been developed at the Thresholds National Research and Training Center (TNRTC) on Rehabilitation and Mental Illness (Cook et al., 1991) presenting a series of vocational assessments used in clinical settings and in research studies. This manual describes each type of assessment along with illustrations of its use, information on reliability and validity, and pertinent literature citations for further reading.

*Linkages between psychiatric symptoms, diagnoses, and employment outcomes.* An issue of interest to those in rehabilitation



*Members of the Thresholds psychosocial rehabilitation program in Chicago help each other find job possibilities listed in the want ads (Photo by Bruce Powell).*

is the connection between employment outcomes and client symptoms and diagnoses. Prior studies in this area had suggested no significant relationship between psychiatric symptomatology, diagnosis, and work performance (Anthony & Jansen, 1984). Yet, recent work suggests that clients' hospitalization histories and diagnoses as "schizophrenic" or "psychotic" (versus other broadly-defined categories, such as "nonschizophrenic" or "neurotic") are associated with poorer vocational outcomes (Grusky, Tierney, Manderscheid, & Grusky, 1985; Liberman, 1989).

One recent study examining work skills, symptomatology, and diagnoses among clients in a psychosocial rehabilitation (PSR) program (Anthony, Rogers, Cohen, & Davies, in press) found higher levels of symptoms, especially negative ones, such as withdrawal or blunt affect, among those subsequently unemployed, although these differences became nonsignificant at the 6- and 12-month assessments. Moreover, clients with higher symptom severity had significantly poorer work skills. No differences were found by diagnosis. In another study, clients most likely to be unemployed at 12 months

were those with schizophrenia versus all other types of diagnoses (Fabian, 1992a). Anecdotal evidence in a forensic mental health program (Evans, Souma, & Maier, 1989) suggests that those with personality disorders benefitted more from inpatient work and community volunteer placements than did those with schizophrenia.

There still is much to be learned about the interaction of diagnosis, symptoms, skills, and job environment. Moreover, additional information is needed about the operation of important covariates such as psychiatric treatment status, individual abilities, prior job skills training, prior work history, rehabilitation services, and traditional labor force predictors, such as ethnicity, gender, education, and social class (U.S. Congress, Office of Technology Assessment, 1994). Because the severity of symptoms does not necessarily correspond to an individual's functional limitations, it is important to develop a

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better understanding of how psychiatric symptoms and diagnosis impact vocational outcomes.

*Effects of employment on self-esteem and life satisfaction.* Increasing emphasis is being placed on development of vocational services and rehabilitation plans that reflect consumer choice (Cook, 1992a). This has resulted from a critique of many of the vocational opportunities offered to people with mental illness, especially entry level employment, a mainstay of many psychiatric rehabilitation programs (Furlong, Jonikas, Cook, & Goode, 1994). This critique, along with the consumer empowerment movement, has focused attention on the aspects of employment that are found to be esteem enhancing, dignifying, and rewarding, as well as financially remunerative (Fisher, 1994; Harp, 1994). This shift has turned attention to outcomes such as life satisfaction, quality of life, and job satisfaction and how these are influenced by work experiences.

Several studies have explored the connection between self-esteem and the employment of people with psychiatric disabilities. One such study examined how the employment status of 88 mental health consumers affected their feelings of self-esteem, life satisfaction, and coping mastery (Arns & Linney, 1993). All three of these personal satisfaction measures were significantly higher among those who had experienced positive changes in employment, such as becoming employed or moving to better jobs. The theoretical model derived from this research was that improvement in vocational status increases feelings of self-efficacy, thereby improving self-esteem, which, in turn, improves life satisfaction. In another study (Hatfield, Huxley, & Mohamad, 1992) those expressing the most dissatisfaction with their unemployment were those living in the community with friends or family. The authors argue that this suggests the important role of social context in defining what individuals will find satisfying in the employment realm.

Another study examined the effects of employment status on quality of life

outcomes of 110 mental health consumers (Fabian, 1992b). Results indicated that having a supported employment job was associated with higher satisfaction on dimensions such as work and finances but not areas such as family, safety, or health. Noting the specificity of effects on some life domains but not others, these researchers warn service providers about the dangers of using work as a panacea for all of a client's problems.

***Increasing attention is being turned to the often unacknowledged "partners" of vocational rehabilitation: the supervisors and coworkers of the client.***

In a separate analysis, employed men but not women with psychiatric disabilities were more satisfied than their nonworking counterparts (Fabian, 1989). This may be due to the fact that life satisfaction for working women is mediated by a number of factors, such as quality of home life and child care, which may lower satisfaction for employed versus nonemployed women with psychiatric disorders. This has been echoed by others (cf., for example, Holstein & Harding, 1992), who argue that the stresses of multiple work roles for women (i.e., home and labor force) are not adequately assessed in level of functioning scales such as the *Global Assessment Scale*.

A focus on job satisfaction among workers with mental illness is long overdue, given its importance to vocational outcomes in the general population (Cook et al., 1991). Clients in one supported employment program (Dantley, Rogers, MacDonald-Wilson, & Anthony, 1994) had especially low levels of job satisfaction, which the authors suggested was possibly due to their underemployment at jobs below their skill levels. In another study, those receiving

job placements within a month had higher job satisfaction (especially with pay) than those who participated in unpaid crews for 4 months (Bond, Dietzen, & McGrew, in press). Both studies noted that satisfaction was higher among clients who were placed more quickly. While this relationship may be causal, with shorter time to placement leading to job satisfaction, it is also possible that both outcomes (higher satisfaction and shorter time to placement) are associated with being higher functioning. This bears further investigation, especially to determine whether any clients need lengthy prevocational assessment and preparation periods and, if so, which clients, and how to target them.

An outgrowth of this focus on satisfaction and quality of life is to view aspiring workers with psychiatric disabilities as similar to any American workers, responding to the same social and personal forces. By deriving satisfaction and self-esteem from their employment in ways similar to other workers, mental health consumers find themselves in a less stigmatizing framework. Such a perspective also encourages researchers and program designers to consider the ways workers with psychiatric disabilities are influenced by regular labor market conditions and constraints (Cook & Razzano, 1995).

*Employer/coworker relationships.* Increasing attention is being turned to the often unacknowledged "partners" of vocational rehabilitation: the supervisors and coworkers of the client (Cook, Razzano, Straiton, & Ross, 1994). Employers are important actors given their influence on a worker's job tenure (Cook, 1992b) and their central role in making reasonable accommodations for their employees (Solomon, 1993). Coworkers comprise the social context at the workplace and are important sources of support and informal learning (Cook, Jonikas, & Solomon, 1992). There is enhanced recognition that both groups are or should be recipients of vocational services along with their disabled coworker, signalling what has recently been called a "paradigm shift"



in the field of rehabilitation services (Molinaro & Walls, 1987).

One type of service to employers and coworkers is training and education, which is part of many of the new vocational models being developed in the psychiatric rehabilitation field. Fabian and Luecking (1991) describe a program designed to train employers to provide long-term job coach supports to workers with psychiatric disabilities. Dauwalder and Hoffman (1991) present another program in which psychoeducational approaches are taught to coworkers and job supervisors. Providing direct services to a worker's so-called "natural supports" is part of the new approach to modifying the job environment for certain workers.

The turn toward natural supports has meant the enlistment of coworkers and supervisors in relationships and arrangements not previously tried for workers with psychiatric disabilities. Promoting mentoring relationships along with ongoing consultation to both mentors and clients is an approach described in one workplace-based program (Fabian & Luecking, 1991). Use of peer job coaches to supervise small work crews in commercial settings has been described in another vocational program (Cook, Jonikas, & Solomon, 1992). This use of interpersonal support may be somewhat unique to psychiatric disability, which seldom requires structural accommodations such as ramps or technological modifications such as assisted communication. Instead, accommodations may more often involve use of interpersonal relationships by adjusting supportive, supervisory, and training interactions to meet the worker's needs (Mancuso, 1991). Future studies are needed to explore the kinds of reasonable accommodations workers with psychiatric disabilities request along with employers' and coworkers' reactions to them.

Given the importance of employers' attitudes about workers with psychiatric disabilities, researchers have continued a line of attitudinal research dating back to the 1950's (Olshansky, Grob, & Ekdahl, 1960). Much of this earlier research indicated extremely

negative attitudes on the part of current or potential employers; in several of these earlier studies, workers with mental illness were ranked last on desirability in comparison to workers with other types of disabilities (Cook et al., 1994). However, a recent study reveals more positive attitudes than might have been suspected from prior research. This study compared the attitudes of a group of 62 employers and matched non-employers of persons with mental illness (Cook et al., 1994). Multivariate analysis revealed that employers had fewer concerns than non-employers about workers with mental illness; they saw these workers as easier to accommodate than did non-employers and were less likely to see employees with mental disorders as having skill or behavior deficits relative to nondisabled coworkers. These authors conclude that those who knowingly hire persons with psychiatric disabilities have more positive reactions to accommodating their disabilities and to working directly with them than a highly similar group of non-employers. If these results are replicated, it may be that longer term exposure to the quality of these workers enhances employers' opinions as "familiarity breeds respect" after direct exposure.

Passage and enactment of ADA has also meant greater scrutiny of the ways in which employers treat workers with disabilities, including those with psychiatric disorders. Data on ADA charges filed between July 1992 through October 1993 indicate that mental illness was the second most frequently cited disability (cited in 10 percent of all complaints). Psychiatric disability had a frequency only lower than back impairments, a disability cited in 19 percent of all filings, and was named twice as often as the next most frequent condition,

heart impairments, which comprised 4 percent of all filings (Equal Employment Opportunity Commission, 1994). This leads to several questions: Do workers with psychiatric disabilities experience disproportionately more discrimination than workers with other disabilities? Are workers with psychiatric disabilities more likely to file ADA complaints than those with other disabilities? Are the *types* of accommodations requested by workers with psychiatric disabilities being rejected with greater frequency by employers than the ramps, interpreters, and aids requested by other disabled workers? The uncovering of any systematic discrimination against workers with psy-



*Satisfaction and pride are outcomes of a job well done by a member of the Thresholds psychosocial rehabilitation program in Chicago (Photo by Bruce Powell).*



chiatric problems may be documented by research on this and related topics.

Those interested in the implications of ADA note that it necessitates disclosure of one's disability to employers in order to support a request for an accommodation (Mancuso, 1993). Such disclosure can have highly negative consequences because extremely high levels of social stigma and rejection accompany psychiatric disorders. For example, a nationwide survey by Louis Harris and Associates, Inc., (1986) found that respondents were least comfortable with persons who had mental illness compared to all other types of disabilities. The "hidden" nature of disabilities such as mental illness and learning disability means that employers may be unaware of the disability before there is a need and request for a reasonable accommodation (Solomon, 1993). The simultaneity of disclosure and request for accommodation may make the process more complex and difficult for all participants. To address this, Mancuso (1993) has prepared a manual of case studies describing different types of reasonable accommodations requested by workers with psychiatric disabilities, along with potential employer reactions. By laying out the rationales of employers who refuse requests for accommodations under the law, the manual offers suggested compromises and resolutions.

On the other hand, disclosure can carry positive benefits, such as diminished shame, enhanced self-esteem, and permission for coworkers to offer support (U.S. Congress, Office of Technological Assistance, 1994). One study of vocational rehabilitation clientele with psychiatric disabilities found that disclosure was related to significantly longer job tenure (Fabian, Waterworth, & Ripke, 1993). Future studies of the disclosure process and outcomes of that process will undoubtedly reveal much about ways in which the timing and nature of disclosure affects reasonable accommodations.

*Growth of individualized models providing ongoing vocational support.* The literature contains many examples of new models designed to take specific

account of the nature of mental illness and to be more sensitive to clients' preferences regarding when they are placed and at what kinds of jobs. Two common features shared by many of these models are their individualized nature and the availability of ongoing supports. These characteristics respond to consumers' desires for employment that is nonstigmatizing, with natural supports rather than obtrusive professional job coaching. Also apparent is the movement away from work in groups, which may draw unnecessary attention to workers' disabilities, to individualized models that are more natural and less stigmatizing.

***Clearly, the twin services of community job placement and ongoing supports have advantages over sheltered workshop and timelimited models.***

The availability of ongoing supports is echoed in many of these models, stimulated perhaps by the importance of supported employment (Cook & Razzano, 1992) as well as a tradition within PSR programs of offering lifelong "membership" (Cook & Hoffschmidt, 1993). Research suggests that the availability of ongoing assistance is critical (Bond & Boyer, 1988). In one study of 550 PSR clients who received vocational rehabilitation (Cook & Rosenberg, 1994), a logistic regression analysis predicting employment status 6 months after program exit found that ongoing support was a significant factor in a model including education, ethnicity, and types of job supports received. Another study of a model program at the same agency (Cook & Razzano, 1992), found that providing as needed, workplace-based employment support to those who held at least one paid job raised the employment rate from 50 percent to above 80 percent

throughout the 36-month program period. A comparative study of 2-day programs providing sheltered work to ex-psychiatric patients (Drake, Becker, Biesanz, Torrey, McHugo, & Wyzik, 1994) found that the one converting to a supported employment approach had superior vocational outcomes compared to the program that continued its original sheltered work model. Clearly, the twin services of community job placement and ongoing supports have advantages over sheltered workshop and timelimited models. However, much more information is needed before we can understand the meaning of some of these findings as principles of service design.

Another principle embodied by many model programs is the importance of swiftly placing clients who are seeking employment. For example, one randomized study (Bell, Milstein, & Lysaker, 1993) found that clients placed into community jobs immediately had better vocational outcomes than those who participated in prevocational crews before placement. Another randomized study found that those supported employment clients who were placed in jobs immediately (Bond, Dietzen, & McGrew, 1993) reported superior outcomes (higher employment rate, higher job satisfaction) than those receiving prevocational services prior to their first jobs. Despite high levels of client satisfaction in one small supported employment program (Danley et al., 1994), participants were most dissatisfied with the amount of time it took to obtain employment. This suggests that the prevocational phases of most models should be examined for usefulness and altered if necessary.

*Development of postsecondary education models.* Along with normalization of work as a goal for mental health consumers has come a growing acceptance of postsecondary education and training for people with psychiatric disability. Given the age of onset of severe mental disorders in the late teens and young adult years, education is a developmentally appropriate goal for this consumer group (Cook, Solomon, Farrell, Koziel, & Jonikas, in press). But



beyond this has come the recognition that career changes may be necessitated by the occurrence of this disability such that without re-education many are forced into entry level employment (Cook et al., 1992). In one study of people with schizophrenia (Navin, Lewis, & Higson, 1989) over one-third (35 percent) had attempted formal education while less than one-tenth (9 percent) had completed their course of study. There is evidence that adults with mental illness need remedial work in reading and mathematics along with ongoing supports for attempting mainstream college or vocational/technical training. For example, screening of one group of clients entering a supported education program (Cook & Solomon, 1993) indicated that over half had reading and mathematical computation skills below the 12th grade level. Yet, postsecondary education is a service seldom suggested for persons with psychiatric disabilities, even though it is commonly used in the rehabilitation of people with physical and communication disabilities (Unger, 1994).

Outcome studies have confirmed the usefulness of postsecondary approaches including academic supports along with mental health services (Jacobs & Glater, 1993; Ryglewicz & Glynn, 1993) in models commonly referred to as "supported education" (Unger, 1994). These programs typically offer remedial and preparatory education, counseling and advocacy, and ongoing support for a variety of educational and case management needs. In one study of 68 supported education students and a group of matched clients receiving identical clinical but no educational services (Hoffman & Mastrianni, 1993), participants were significantly more likely than the comparison group to return to college and to do so full-time. In a followup study of 52 supported education clients (Unger, Anthony, Sciarappa, & Rogers, 1991), significant increases over baseline were found in college class enrollment, competitive employment, and self-esteem. A third outcome study of 102 supported education students (Cook & Solomon, 1993) found that 78 percent

of the participants were employed during the program and showed significant increases in both hourly wages and number of hours worked per week. Compared to their scores at pretest, these clients also had significantly higher self-esteem and coping mastery after participating in the program.

As with employers, postsecondary education involves the cooperation of silent partners, such as faculty, administrators, and other students. Several programs have explored the role of faculty inservice training for integrating students into college and vocational education settings (Jacobs & Glater, 1993; Wolf & DiPietro, 1992). Results of one field test of a faculty inservice on working with students with psychiatric disability (Cook, Yamaguchi, & Solomon, 1993) revealed that training significantly improved knowledge levels and attitudes toward these students.

As the field begins to look beyond entry level employment for people with psychiatric disabilities, the role of supported education services will become increasingly important. Past experience has indicated that many people with psychiatric disabilities need assistance to succeed at college or technical training. Now that the techniques for providing this support are available, it remains to be seen whether or not they become readily available to clients who need them.

*Consumer-delivered vocational services.* Another recent trend in vocational service design is consumer-delivered employment services, including consumer-run businesses (Warner & Polak, 1993), use of consumers in vocational staff positions such as job coaches (Cook, Jonikas, & Solomon, 1992), and consumer-run vocational rehabilitation programs (Allen, 1994). These types of approaches build on recent findings (McGill & Patterson, 1990; Sherman & Porter, 1991; Solomon & Draine, in press) indicating the effectiveness of consumers as providers of mental health services. Extending these results to provision of vocational rehabilitation services, new programs around the country are exploring ways in

which consumers can offer employment training and supports.

One report describing the establishment of nine Pennsylvania Department of Mental Health-funded consumer-run drop-in centers (Kaufmann, Ward-Colasante, & Farmer, 1993), detailed the vocational components of their programming. With quite minimal funding (the average center award totaled just \$16,500 per year), each center helped its consumers prepare resumes, obtain job leads, negotiate the job search process, and maintain jobs over time. Some offered supported work, training in word processing, or job placement services. A followup report on the nine projects 1 year after startup (McCormack, 1992) found that 18 percent of all clients (N=123) had participated in some form of unpaid work performing drop-in center functions; 7 percent (N=48) had received job seeking skills training; and 4 percent (N=25) had received assistance following up job leads. Regarding employment outcomes, 4 percent (N=25) acquired full- or part-time jobs outside their centers while another 5 percent (N=29) were employed within their centers. The followup study noted that scarce financial resources and limited vocational training of center staff and volunteers were impediments to development of more effective services. Also noted was an extremely high level of vocational interest among center clients coupled with frustration among consumer staff because limited resources prevented them from providing higher quality employment services.

Another project, based in Pittsburgh and called The Self Help Employment Center, uses a model combining peer supports in conjunction with professionally provided vocational services (Kaufmann, Roth, & Cook, 1992). Consumers in this project provide job skills training and counseling to program clients coupled with job development and ongoing supports from nonconsumer providers. In a randomized study comparing this model to "customary vocational services," preliminary results indicated that those in the experimental condition showed significant improvements in employment





*Helping children learn how to share is one skill taught by parents in the Thresholds Mothers Project for women with mental illness and their children, located in Chicago, Illinois (Photo by Bruce Powell).*

status over time in comparison with control group clients (Kaufmann, 1995).

A project in upstate New York uses consumers to train other consumers as crisis workers in a hospital diversion program (Dumont, Shern, & Blanch, 1993) and is being evaluated using a randomized design. A consumer-run cooperative in Boulder County is described by Warner and Polak (1993), in which consumer and nonconsumer staff work together in a property maintenance and repair business contracted by the local community mental health

center. In Washington, D.C., the On Our Own Computer Center uses consumer staff to train mental health consumers for computer careers and employs them directly in contract work arranged with local businesses (Allen, J., personal communication, July 26, 1994).

As part of its growing role in shaping mental health and rehabilitation services, the consumer/survivor empowerment movement has encouraged the development of consumer-delivered vocational services. Such approaches offer the benefits that come

from providing peer role models for vocational rehabilitation clients, as well as staff with the insight that comes from direct experience as consumers. While studies are underway to investigate the effectiveness of these approaches, new projects continue to be developed using consumers as rehabilitation service providers.

*Special populations: Women, ethnic minorities, and youth.* Along with normalization of employment for persons with psychiatric disabilities has come recognition of diversity among this clientele. Increasing awareness of how gender, race, and age impact the employment outcomes of those with psychiatric difficulties has spurred interest in these groups.

The focus on women stems from the new research on female clients with mental illness and their comparative outcomes with men. A study of employed and unemployed mental health consumers (Fabian, 1989) found the highest satisfaction among employed men and the lowest among employed women. This latter finding has been attributed to the multiple roles occupied by women more often than men, such as domestic and child rearing responsibilities (Fabian, 1989). In a similar vein, Holstein and Harding (1992) argue that most level of functioning assessments fail to adequately measure the stresses associated with women's greater likelihood of multiple roles. This failure to assess more than the formal work role misses symptoms and stressors associated with childcare, housework, and family care. This, in turn, may contribute to less accuracy in research on women mental health consumers.

Research concerning the impact of gender on employment outcomes has been inconclusive. Earlier research had found a lower proportion of women employed at significantly lower income than men (Test & Berlin, 1981). A followup study of 260 women 6 months after discharge from psychiatric hospitalization (Goering, Cochrane, Potaszniak, Wasylenki, & Lancee, 1988) found no differences in employment status; however, women were more likely to be employed in clerical or sales



positions while men were more likely to work in skilled or semi-skilled occupations. Other studies have found that gender was not a significant predictor once other factors such as marital and parental status had been controlled (Cook & Rosenberg, 1994; Razzano & Cook, 1994). However, several studies across many different types of disabilities have shown that, as a group, women with disabilities have significantly lower employment rates and lower salaries than their male counterparts (Danek, 1992; Menz, Hansen, Smith, Brown, Ford, & McCrowey, 1989; Vash, 1982).

***Several studies suggest that client ethnicity influences employment outcomes.***

Several studies suggest that client ethnicity influences employment outcomes. In a discriminant function analysis of 653 clients in a PSR transitional employment program (TEP) (Cook & Razzano, 1995), minority participants (80 percent of whom were African American) were significantly less likely than their white counterparts to have graduated from TEP placements to competitive employment. In multivariate models predicting hourly salary and job level (Cook & Roussel, 1987), Caucasians earned significantly more and achieved higher level jobs than minorities (predominantly African Americans) despite controlling for characteristics such as work history, illness history, and demographic features.

If ethnic minority clients receive lesser benefits from vocational rehabilitation efforts, they may be more dissatisfied with the jobs they obtain through these services. It is perhaps not surprising, therefore, that higher life satisfaction was found among unemployed than employed minority mental health consumers in one study

(Fabian, 1989) while the opposite was true among Caucasian consumers.

Increasing attention has been focused on transition aged youth with emotional and behavior disorders. This has stemmed from federal policy initiatives for decreasing service fragmentation and overutilization while improving standards of mental health care for children and adolescents (Collins & Collins, 1990; Weithorn, 1988). Additional impetus has been provided by the passage of recent legislation mandating the transition of youths with disabilities from school to employment or postsecondary school settings (Cook, Jonikas, & Solomon, 1992; Wermuth & Cook, 1992; Will, 1985). The challenges of comprehensive service delivery to this population stem from the need to coordinate several large systems of care: mental health, education, and rehabilitation.

In a number of statewide studies in which special education students were followed up after high school, youths with severe emotional disturbances (SED) and behavior disorders (BD) have poorer outcomes than comparison groups (Mithaug, Horiuchi, & Fanning, 1985; Neel, Meadows, & Levine, 1988). In 1987, a National Longitudinal Transition Study (NLTS) of Special Education Students began, mandated by the U.S. Congress and funded through the Office of Special Education Programs (OSEP), U.S. Department of Education (Wagner, 1989). Conducted by SRI International, this study is producing the first national information about the secondary and postsecondary experiences of youth with disabilities, including those classified with SED (Wagner, 1989). Results thus far indicate that among 12 types of disability, students with SED constituted the highest proportion of high school dropouts, the highest proportion of students with one or more failing grades, and the fourth lowest percentage of students in postsecondary education (higher only than students with multiple disabilities, those who are deaf/blind, and those who are mentally retarded). The most recent data from this study (Wagner, 1993) indicate that SED youths made fewer gains in employ-

ment and had more unstable work histories than all other subgroups.

In addition to poor outcomes for youth classified as SED/BD, this same research reveals poorer results for female than male youths with disabilities. Earlier followup studies of special education students (Mithaug & Horiuchi, 1983) found that females were less likely to be working, to have received bonuses for working, or to have left a job to take a better one. This has been confirmed recently by the NLTS finding that female respondents were less likely to be working full time or to be earning more than \$6.00 an hour and less likely to see friends frequently or be involved in groups (Wagner, 1993). Results regarding gender differences among the SED/BD subgroups have not yet been published.

## **A Look Toward the Future**

After years of benign neglect by the fields of mental health and rehabilitation, psychiatric rehabilitation is coming into its own as we near the end of the 20th century. First, it has shed the mantle of lowered expectations in which persons with psychiatric disability were viewed as those for whom entry level employment was deemed a "success" because of its integrated nature. The notion of careers for workers with psychiatric disabilities is being explored in many fields, including the social and rehabilitation service professions. Today, public attitudes toward people with a wide range of disabilities and their roles as workers are changing. Such shifts in work force attitudes are likely to benefit mental health consumers who battle the stigma surrounding their disability. This shift in opinions about who belongs in the workplace could be responsible for increasing levels of acceptance of workers with psychiatric disabilities by others.


The development of drug regimens which are effective for many workers (though not without troublesome side effects) (Rutman, 1994) and increased knowledge about how to develop jobs and provide onsite sup-



ports for workers with psychiatric disabilities (Furlong et al., 1994) have opened up a wider range of employment opportunities. This trend, in turn, is being bolstered by provisions of ADA which mandate fair hiring practices and reasonable accommodations for these workers. Along with this, a movement of mental health consumer activism has led to consumer-run businesses and other vocational services delivered by and to consumers. These, in turn, have nurtured the employment goal for a wider and wider range of clientele.

How the vocational rehabilitation field responds to this newly politicized, increasingly assertive, and more "service-savvy" group of consumers remains to be seen. The use of older models in which clients engage in long periods of prevocational preparation or where they are offered sheltered or temporary work before integrated, permanent jobs may be questioned by these clients. Also viewed with skepticism will be vocational assessments with limited predictive validity and demonstrated gender and ethnic biases. Clients may increasingly demand supported education services to complete interrupted schooling or acquire needed postsecondary training. All of these trends suggest that client choice will become more and more important in the near future. A strong emphasis on client choice is contained in the provisions of the recently reauthorized Rehabilitation Act (Furlong-Norman, 1993), which affords client preferences and goals a primary place in the rehabilitation planning process. It remains to be seen how much choice clients will actually have, however, in an era of shrinking service delivery dollars, organizational downsizing, and cutbacks in funding.

The field of vocational rehabilitation for people with psychiatric disabilities is characterized by tremendous potential. Yet the growth of new approaches has heretofore been hindered by a lack of valid, reliable knowledge about effective rehabilitation practices and how to encourage them. The most recent research offers many promising and sug-

gestive avenues for program development and further study. 

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# Strategies to Increase Job Tenure for People with Psychiatric Disabilities:

## An Overview of *The Back To Work Program*

***This article presents an overview of one program's techniques for increasing job tenure for people with psychiatric disabilities. The Back To Work Program (BTW) of St. Luke's House, Inc., has used a combination of successful supported employment models to increase job tenure. Program design and philosophy, consumer choice and responsibility, coordination of services, and the relationship with the business community are presented as primary components of the program.***

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**I**t is well documented that people with psychiatric disabilities have the lowest rate of successful vocational rehabilitation of any consumer population. A National Alliance for the Mentally Ill (NAMI) study surveying relatives of people with psychiatric disabilities revealed that only 5 percent of their relatives with mental illness were competitively employed on a full-time basis (Spaniol & Zipple, 1988). This poor success rate occurred despite the fact that 92 percent of these people had high school degrees and 60 percent had either post high school or college training. Similarly, in a survey of 99 long-term psychiatrically disabled consumers, Spivak, Slaver, Deuschle, and Garrett (1982) found that only 13 percent were working on more than a half-time basis.

In recent years, considerable effort and funding have gone into creating supported employment programs to address these problems. This article is based on the practical experiences and techniques that have been used by one agency to support its consumers in maintaining employment. *The Back To Work Program* of St. Luke's House, Inc., supports adults with long-term mental illness in obtaining regular competitive jobs in the community. Located in Bethesda, Maryland, BTW has been providing supported employment services for the last 8 years. Originally a residential program, St. Luke's House began offering vocational services in 1982. From 1982 to 1987, job placement services were offered to residents with

the highest level of interest and motivation. An accurate description of services during this period was "place and pray." At that time, consumers of these services were employed at a rate of 50 percent. With the arrival of supported employment funding in 1988, *The Back To Work Program* was developed. The program adopted a zero rejection model and began receiving funding from Maryland's Division of Vocational Rehabilitation. By 1990, the program had developed a specialized evaluation for supported employment, *The Business Cluster Model* (Barker 1994), an employment rate of 75 percent, and an average length of employment of over a year. Today, BTW offers a continuum of vocational services including vocational evaluation, transitional employment, job search and job keep groups, and supported employment. The program is also a part owner of a Mail Boxes Etc. franchise. As BTW has expanded the average length of stay on the job has increased to over 17 months.

BTW has combined portions of the *Fountain House Model*; *The Boston University Choose, Get, Keep Approach*; and *The Assertive Community Treatment Model of Vocational Rehabilitation* (Barker, 1994). These models, among others, were discussed in a 1992 conference sponsored by the National Institute for Disability and Rehabilitation Research. This conference, entitled "Strategies to Secure and Maintain Employment for

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People with Long-Term Mental Illness," attempted to define the most current data and empirically based knowledge concerning variables that positively influence the vocational rehabilitation and employability of people who have severe psychiatric disabilities (Danley, 1994). All three of these models have produced successful outcomes independently.

From the Boston University model we have adopted a standard psychiatric rehabilitation practice of functional assessments, measurable goals, and an emphasis on consumer choice. From the Fountain House model we have added transitional employment positions. From the ACT model we incorporated the practice of an integrated treatment approach and the commitment to long-term support. The BTW experience has shown that even higher outcomes are possible when a combination of the three models is used along with a customer service focus toward employers and consumers.

The purpose of this article is not to promote a specific model of vocational rehabilitation but to discuss qualities of *The Back To Work Program* that lead to increased job tenure. The four key characteristics of BTW are described below.

## Program Design and Philosophy

BTW has chosen to task job coaches with a full range of supported employment services, including comprehensive vocational evaluations, goal planning, job development, job placement, job coaching, and follow along. Because of the nature of these responsibilities, the job title has been changed from job coach to supported employment specialist (SES). In many programs, there are vocational evaluators, transitional employment program (TEP) placement managers, job developers, and follow along staff. BTW has found that what is lost in specialized skills is regained in the relationship and trust between the consumer and the SES and that this relationship is a key ingredient in obtaining and keeping jobs. With a current staff-to-consumer ratio of 1 to 10, BTW staff work as a

team both in the job search phase and in the job keep phase. They are empowered to schedule their activities independently but are clear that their first priority is to support consumers in keeping jobs. Mutual support of staff is a key component to reducing burnout and having consumers benefit from the sum of staff expertise.

***BTW's guiding principles start with the belief that any consumer who walks in the door is capable of being successfully employed.***

BTW's guiding principles start with the belief that any consumer who walks in the door is capable of being successfully employed. Work itself is considered treatment, and vocational services are integrated into the treatment team. Consumers benefit from having clear and measurable goals based on choosing, finding, and keeping a job and job match is based on the consumer's interest, preference, and skill level. Support services need to be flexible and available on a long-term basis. The consumer and the employer are treated as customers. Job coaching services are delivered in a fashion to minimize stigma and facilitate supervisor and coworker involvement. Any support that can be given naturally rather than by a paid professional is optimal.

## Consumer Choice and Responsibility

An important element in assisting mental health consumers in developing

job tenure is the consumer's investment in his/her own vocational rehabilitation processes. Consumers who are invested in their individual vocational pursuits naturally will do better in their jobs. To foster this investment *The Back to Work Program* encourages the personal choices of the consumer in career direction and job development efforts.

Much work is devoted to assisting consumers in making their vocational choices. Initially, this work begins in the evaluation process with work histories and interest inventories. This process helps the potential employee begin to make informed choices which will later develop ownership and the assumption of responsibility for keeping (or losing) the job. Informational interviews and work trials are excellent devices to help consumers gain firsthand knowledge of various employment areas. Investing time and effort in assisting the consumer in the development of appropriate job choices often extends the job development process but results in increased longevity on the job once it is obtained. This investment is a welcome trade-off for virtually all BTW consumers.

Choosing an appropriate type of work is essential in establishing job tenure. However, the consumer faces a myriad of choices during the rehabilitation process. Each decision made by the consumer is important in that decision making itself contributes to a sense of ownership in the various phases of supported employment.

One of the first of these choices is the decision to disclose or not to disclose one's disability and the need for job coaching support. This is a very personal decision that should be considered with a counselor's assistance but can only be made by the consumer. This decision will determine the nature of support that is provided onsite and offsite as well as the type of relationship the counselor may have with the employer. Having such input encourages the consumer to welcome support rather than resist it and consequently has a very direct impact on job tenure. The consumer is invested in determining the type of support that is



provided and develops a sense of ownership of the vocational support plans.

A consumer's recognition that this job is part of a chosen career plan greatly enhances the potential for tenure in a given job. The consumer is able to view the placement as a means, not merely an end, and is often able to make a more substantial commitment as a result. BTW supports consumers in resigning from jobs that they find to be inappropriate in some way, or that do not meet their career objectives. Consumers are assisted in making these choices and in leaving their jobs in a professional manner if they so decide.

The program values a high degree of consumer investment and participation in the job development process. This is often described as the "50-50 philosophy" and depicts the expectation that consumers will work as hard on their job search concerns as their SES. Supported employment specialists often remind potential employees that they will receive assistance in their job search, but that they will not be "given a job." This serves to illustrate to consumers that their own commitment to the job is essential if they are to experience success in finding and maintaining employment.

BTW consumers assisted in developing their own strategies of vocational support to address work-related difficulties. This again contributes to a sense of ownership throughout the rehabilitation process and enhances the capacity to develop long-term job tenure. When someone has difficulty developing strategies and solutions, they are assisted in identifying an array of choices to support their own sense of empowerment regarding work. Regardless of the final decision, the consumer experiences a feeling of control that enhances the development of self-confidence so essential to establishing job tenure.

Ultimately, consumer choice in vocational rehabilitation empowers the new employee with an awareness of responsibility that results in more dedication and commitment to the job. It is natural that people work harder to keep

things that they have strived for and are not merely provided.

## Coordination of Services

For the purposes of this article, coordination of services shall be deemed to include all the collaborative efforts made by members of the consumer's treatment team to support the consumer in his/her vocational success. Because many consumers of mental health services are involved with a variety of service providers, it is important that these providers keep in regular contact with one another throughout their work with that consumer. This group of service providers is commonly referred to as the "treatment team" and may include vocational rehabilitation counselors, employment specialists, case managers, employers, therapists, psychiatrists, and Alcohol Anonymous sponsors, among others.

Previous research has supported the importance that coordination of services can have in the vocational rehabilitation of people with mental illness (Jones, 1986). Dellario (1985) looked at interagency functioning between mental health agencies and the state division of vocational rehabilitation. His results suggested that improved mental health-vocational rehabilitation interagency linkages can increase the probability of successful rehabilitation outcomes for people with psychiatric disabilities. Further, Rao, Kaplan, Harvey, and Jellinek (1982) showed that a cooperative relationship between a psychiatrist and a trained rehabilitation counselor during the evaluation and planning phases resulted in better vocational rehabilitation outcomes.

It is the BTW philosophy that coordination of services should continue throughout the consumer's entire rehabilitation. Effective coordination among all service providers can help consumers to maintain long-term employment in many ways. Regular contact ensures that the consumer is not overloaded and that each individual program is a support to the other programs and the consumer. Frequent contact can also help to identify potential

problems before they occur and therefore contribute to a culture of preventative rehabilitation.

***Coordination is critical throughout the job choice, search, and keep phases of employment.***

Coordination is critical throughout the job choice, search, and keep phases of employment. Providers may have information on the consumer's vocational past or more general history on the consumer's interpersonal skills that may be critical to selecting a good job match. Psychiatrists and other medical doctors are consulted to determine how many hours and in what kind of environment a person can work. Beginning in the vocational evaluation phase, employment specialists should be required to contact all service providers, including family members and at least three previous employers, if possible.

The importance of these practices is reinforced by Rogers, Anthony, and Danley's (1989) research, which demonstrated that increased mental health-vocational rehabilitation collaboration led to a decrease in consumer referrals and an increase in number of consumers rehabilitated. The increased communication between agencies apparently resulted in a reduction of inappropriate referrals. For these reasons, a treatment team meeting should be arranged to discuss the vocational evaluation and to establish uniform goals for choosing, finding, and keeping a job.

In addition to valuable insight, the treatment team will be needed to provide support to the consumer around



work issues even when the consumer is not at work. Coordination is essential for someone maintaining employment because an integrated work environment is often less tolerant of certain behaviors than other environments. For example, one employee may be working with his SES who is helping him to arrive at work clean shaven, showered, and neatly dressed. Residential counselors or case managers who also work with this consumer might create goals around waking up on time, laundry skills, and personal hygiene.

If both programs address the issues independently, different approaches may confuse or overload the consumer and prevent success instead of encouraging it. Similar overlap can occur with interpersonal issues like communication and anger management. It is critical for employees to know how to manage anger on the job, and the SES can help to find options while at work, but it would make sense for this also to be a topic discussed in therapy. A coordinated treatment team also supports consumers in focusing on one thing at a time. If providers talk to each other regularly and see themselves as a team, natural priorities will occur and decisions can be made on what are the current support needs.

At BTW, employment specialists focus many of their efforts towards helping the treatment providers visualize the role of work in the consumer's overall welfare. Much of the emphasis in current community mental health is placed on maintenance outside the hospital, and, as research has shown, many programs rate their effectiveness in terms of hospital recidivism.

Hospitalizations often occur when a consumer's stress level is increased; therefore, therapists are concerned with helping consumers reduce stress. Starting and maintaining work can be very stressful, and vocational programs must work closely with therapists when advocating that consumers explore increasingly stressful environments. Research has shown that a consumer's need for support increases during the first 6 months on the job, indicating the need for preparatory work by the SES.

Supported employment specialists involve other team members in the vocational rehabilitation process by explaining how employment promotes community integration. They work to provide consistent and reliable assistance to both the consumer and the treatment team and enlist team members in specific tasks that will help the consumer acquire and maintain employment.

***The idea of creating strong relationships between employment specialists and the business community is not new.***

### **Relationship with the Business Community**

*The Back To Work Program* also assists consumers in maintaining long-term employment by developing good relationships in the business community. People trust others who know and understand their needs and who have demonstrated a concern for these needs. The business community is no different. For these reasons, BTW has found it important to become active participants in their local business communities.

The idea of creating strong relationships between employment specialists and the business community is not new. For years, researchers have talked about the need for job developers to adopt a marketing or service-oriented approach to the employment of people with disabilities (Ninth Institute on Rehabilitation Issues, 1982; Garvin, 1983). Following these ap-

proaches, employment specialists encourage employers to hire people with disabilities not because of their "humanitarian good will," but because it makes good business sense. Others have spoken about the myth that employers are not interested or are afraid of hiring people with disabilities.

The Americans with Disabilities Act (ADA) brought many of these fears to light as people argued that the business community would feel undue pressure to hire people with disabilities if this law were passed. More recent studies have shown, however, that the business community is not against ADA and hiring people with disabilities. They just do not know how to do it (Satcher & Hendren, 1991). In a study of persons preparing to enter the business field, Satcher and Hendren (1991) found "acceptance of ADA," but warned, however, that this acceptance "may not result in improved employment opportunities for persons with disabilities unless employers are trained about the legislation's requirements." The business community is definitely in need of this training and support. A recent survey of Fortune 500 corporate policies revealed that among the companies responding, fewer than 25 percent actually had a policy concerning the hiring of people with psychiatric disabilities (Jones, Gallagher, Kelley, & Massari, 1991).

As this research has clearly shown, changing the community's perception of hiring people with psychiatric disabilities from an act of charity to a service for business can help to generate many opportunities for potential employees. For example, *The Back to Work Program* has created the *Business Cluster Model of Supported Employment*. In this model, supported employment specialists become members of several local chambers of commerce and regularly participate in the chambers' functions. Supported employment specialists attend networking breakfasts and market their services as a support for the business community. As well, several supported employment specialists are involved in committees to advocate for the needs of the chambers, including fundraisers and planning committees. One staff



member is on the marketing committee for a chamber; another is on the board of directors. This contact creates long-term relationships between BTW and the business community. Therefore, when job placements are made for consumers within this business cluster, chances are higher for problems to be worked through without dismissal. As mutual involvement in projects increases, business cluster members learn to depend on BTW for technical assistance in helping their employees.


Advancing this philosophy further, BTW has joined hands with business by becoming a limited partner in a Mail-Boxes Etc. franchise. This relationship connects BTW's reputation with understanding and knowing business and also provides consumers with a realistic, yet supportive, training ground for retail work.

With all of this involvement in the business community the supported employment agency and its workers learn what is expected by managers and coworkers and are therefore better suited to relate this information to their consumers. By being involved in the business world, the supported employment SES gains an appreciation and understanding of the customer service mind set. The norms of the business community are internalized for the SES and then passed on to the consumers.

BTW's emphasis on developing business savvy does not start when an SES is hired. BTW recruits and hires individuals who have had connections with business in the past. Having staff who have been involved with business settings before helps keep the program focused on serving the business community and readying consumers to deal with employers. Potential supported employment specialists should have experience in counseling skills, prior experience with the same population, and some private sector business experience. Their training for the position will integrate all three of these aspects.

## Conclusions

Implementing specific techniques to increase the job tenure of people with

psychiatric disabilities should be as important as the job placement responsibilities of employment specialists. A commitment to increasing job tenure begins with program design and philosophy. Programs need to prioritize long-term job-keep skills instead of focusing solely on placement. Consumers and employment specialists need to work closely to develop a trusting relationship where each can challenge the other to work as independently as possible to achieve the consumer's goals. Employment specialists should support consumers to find their own jobs and then work with the employer to promote a successful work environment. Similarly, a strong trusting relationship must be developed with the business community by having employment specialist market their services to employers. Finally, vocational programs need to take the responsibility to insure that each consumer's treatment team is unified, informed, and working towards the same goal of vocational independence for people with psychiatric disabilities. 

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# Recovery and Rehabilitation of Persons with Severe Mental Illness: A Vision

*Although some progress has been made to counteract the myths, misperceptions, and stereotypes surrounding mental illness, stigma still prevents many people from seeking treatment and causes countless others to keep their conditions secret for fear of losing their jobs, health insurance, or homes. This article describes the mission of the Center for Mental Health Services and its current initiatives in the area of vocational rehabilitation. A model mental health service system is described with particular emphasis on the involvement of mental health consumers in designing and implementing the services. The article concludes with discussion of the emerging vision of the future of psychiatric rehabilitation services.*

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Statistics regarding the number of children with emotional disturbance and adults with mental illness and the subsequent impact on productivity are overwhelming.

- Approximately 9–13 million children and adolescents (14–20 percent) from birth through age 21 have a diagnosable emotional disturbance and require mental health services (Brandenburg et al., 1990). Yet, less than one out of five receive appropriate care (Office of Technology Assistance, 1986).

- During any given year, more than 40 million adult Americans are affected by one or more mental disorders; 5.5 million Americans are disabled by severe mental illness, such as schizophrenia, manic-depressive illness, and severe depressive disorders (Bourdon et al., 1992).

- Even by conservative estimates, up to 600,000 people are homeless throughout the country on any given night (Burt & Cohen, 1989). One-third are estimated to be adults with serious mental illness (Manderscheid & Rosenstein, 1992; Tessler & Dennis, 1989).

- For people with mental illness, the unemployment rate is estimated to be 85 percent (Orrick, 1992, President's Committee on Employment of People with Disabilities).

- Morbidity costs—the value of goods and services not produced because of mental disorders—was estimated at \$63.1 billion for all mental disorders in 1990; schizophrenia alone accounted for \$10.7 billion (Rice & Miller, 1993).

- At least two-thirds of elderly nursing home residents have a diag-

nosis of at least one mental disorder (National Institute of Mental Health, 1992, 1990).

- Between 6 and 14 percent of the correctional population are estimated to have major psychiatric disorders (Government Accounting Office, 1991b); 61,000 inmates of state adult correctional facilities received psychiatric care or lived in separately designated housing units (National Institute of Mental Health, 1992).

## The Center for Mental Health Services

The 1992 Alcohol, Drug Abuse, and Mental Health Administration Reorganization Act (Public Law 102–321) established the Center for Mental Health Services (CMHS) to provide national leadership for the treatment and prevention of mental illness. The act mandates vigorous federal leadership in mental health service delivery and policy development. CMHS is a component of the Substance Abuse and Mental Health Services Administration, one of eight Public Health Service agencies within the U.S. Department of Health and Human Services.

The center pursues its mission by helping states improve and increase the quality and range of treatment, rehabilitative, and supportive services for people with mental illness and their families and communities. Congress further provided support for a wide range of programs to respond to the increasing number of mental, emotional, and behavioral problems among America's youth and for programs of outreach and case management to serve hundreds of thousands of Americans who are homeless and severely mentally ill. In addition, the center sup-



ports efforts to create and enhance the effectiveness of consumer run and self-help alternatives (CMHS, 1993).

## Definition of Serious Mental Illness

Clearly, the development of quality programs and supports for adults with serious mental illness and children with serious emotional disturbance is a CMHS priority. As part of the CMHS mandate, Congress required the development of a common definition of serious mental illness. This permits uniform estimates of the number of adults with serious mental illness and children with serious emotional disturbance and encourages comprehensive planning for mental health services to address multiple needs.

The new definition encompasses two parameters:

- the disorder itself, and
- the impact of the disorder on functional status.

The definitions for children and adults are identical, except for age and type of functional impairment.

Children with serious emotional disturbance are defined as persons "from birth up to age 18 who currently or at any time during the past year have had a diagnosable mental, behavior, or emotional disorder of sufficient duration to meet diagnostic criteria specified within DSM-III-R that resulted in functional impairment which substantially interferes with or limits the child's role or function in family, school, or community activities." Functional impairment for children is defined as "difficulties that substantially interfere with or limit a child or adolescent from achieving or maintaining one or more developmentally appropriate social, behavioral, cognitive, communicative, or adaptive skills."

Adults with serious mental illness are similarly defined except they are age 18 and over and their functional impairment "substantially interferes with or limits one or more major life activities," including basic daily living skills such as maintaining a household, managing money, getting around the



*Consumers should be encouraged to participate in the living and leisure time activities of the community. (Photo courtesy of Green Door; photographer, Claire Flanders. Green Door is a community program that prepares people with mental illness to live independently.)*

community and taking prescribed medication, and functioning in social, family, and vocational-educational contexts" (*Federal Register*, 1993).

The term "severe" mental illness is a subset of "serious" mental illness. Severe considers the duration of the disability (i.e., has lasted or can be expected to last 1 year or longer) and has a higher threshold for the disability itself.

## Model Mental Health Service System

Mental health service delivery systems too often lack the necessary resources to prevent or treat the mental

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health problems of youth and adults with either serious or severe mental illness. In the past, children with serious emotional disturbance and adults with severe mental illness were commonly confined for long periods of time at institutions that were often far from home and provided only custodial care. Unfortunately, this still happens today, despite the fact that significant gains have been made in creating community based psychiatric rehabilitation programs. In the late 1970's, a special federal initiative was launched that was designed to assist states and communities to develop a range of basic community services and supports for persons with severe mental illness. This has become known as the *community support system* (Stroul, 1988).

A community support system is defined as "an organized network of caring and responsible people committed to assisting persons with long-term mental illness to meet their needs and develop their potentials without being unnecessarily isolated or excluded from the community." This network includes a spectrum of treatment, life support, and rehabilitation services (Stroul, 1988).

Briefly, the components of the community support system include:

- *Client Identification and Outreach*
  - client identification
  - outreach
  - transportation
- *Mental Health Treatment*
  - diagnostic evaluation
  - supportive counseling
  - medication management
  - substance abuse services
- *Crisis Response Services*
  - crisis telephone services
  - walk-in crisis services
  - mobile crisis outreach services
  - crisis residential services
  - inpatient services
- *Health and Dental Care*
- *Housing*
  - supportive housing
  - residential assistance for homeless persons
- *Income Support and Entitlements*
- *Family and Community Support*

- support and assistance to families
- support and education for the community

- *Rehabilitation Services*
  - social rehabilitation
  - vocational rehabilitation
- *Protection and Advocacy*
- *Case Management*

### CMHS Activities Related to Vocational Rehabilitation

Effective employment interventions are a central component of the community support system model. CMHS's community support program (CSP) facilitates the development of vocational rehabilitation services for persons with serious mental illness through funding of state demonstration projects. From 1989–1994, CSP funded six services research demonstration grants to evaluate models of organizing and providing rehabilitation services and two service system improvement grants for training and education for consumers.

Within the area of services research, a grant in New Hampshire supports a

***A service system improvement grant in Ohio seeks to empower other consumers through a job search and preparation program using consumers as job search specialists.***

model of vocational rehabilitation—Individual Placement and Support (IPS)—for persons with severe mental disorders that combines supported employment with assertive community treatment. A training manual has been produced on how to set up and implement such an IPS program in a community mental health center (Becker and Drake, 1993).



*Every consumer has the right to live a meaningful and productive life and to be given every opportunity to do so. (Photo courtesy of GreenDoor; photographer, Kris Ruckdeschel.)*



A project in Michigan is designed to show how vocational services can effectively be added to existing community support programs. Vocational and case management staff are teamed to promote and maintain vocational placements and supported work initiatives.

In Massachusetts, a project is comparing the efficacy and costs of an experimental psychiatric vocational rehabilitation (PVR) program model with standard vocational rehabilitation services. PVR provides a month-long pre-vocational phase of campus instruction followed by an 18-month period of comprehensive services.

A service system improvement grant in Ohio seeks to empower other consumers through a job search and preparation program using consumers as job search specialists. CSP will disseminate a monograph of executive summaries of final project reports in late 1995.

CSP also works with state mental health authorities to foster new community initiatives and encourages projects to collaborate with federal and state vocational rehabilitation agencies. In a number of states, interagency agreements between mental health and vocational rehabilitation agencies have been signed to provide additional, non-mental health resources for persons with serious mental illness.

Through joint funding with the National Institute on Disability and Rehabilitation Research, CMHS supports two national rehabilitation research and training centers. One is the Thresholds Research and Training Center in Chicago; the other is the Boston University Center for Psychiatric Rehabilitation.

Thresholds has published a manual entitled *Assessing Vocational Performance Among Persons with Severe Mental Illness: A Handbook of Clinical and Research Assessments*. The first section includes vocational assessment and ongoing case logging tools. Instructions and suggestions for their use are provided, as well as mechanisms for planning and tracking psychiatric vocational services. The second section contains a basic introduction to measurement of variables often studied in employment research involving persons with disabilities, es-



*Consumers should be encouraged and accepted as copartners in service provision. (Photo, courtesy of Green Door; photographer, Marilu Halmandaris, Caring Magazine.)*

pecially psychiatric disabilities (Cook, et al., 1994). *An Overview of Vocational Research Activities* conducted by the Boston University Center for Psychiatric Rehabilitation (Anthony, 1994) offers 40 references to published books, book chapters, and articles in the area of vocational rehabilitation and psychiatric disabilities.

A recent CSP Request for Applications solicited proposals for demonstration projects to conduct multisite, cooperative studies of interventions to enhance competitive employment opportunities. Funded projects will develop, implement, and evaluate the interventions (CMHS, 1994).

Within its mission of facilitating the application of findings and practice-based knowledge, improving access, and reducing barriers for people with psychiatric disabilities, CMHS convened in early 1995 a 2-day round table discussion, "Psychiatric Disabilities, Employment and the ADA: Turning Policy into Practice." Consumers, employer representatives, and legal and mental health experts examined and addressed practical issues of implementing Title I

of the Americans with Disabilities Act for people with psychiatric disabilities. Major conclusions of the discussion will be published and disseminated for use in future education and technical assistance efforts.

## Values

Central to all service provision for persons with severe mental illness in the community support system is an underlying philosophy about how such services should be made available. The development and provision of mental health services should incorporate the following values and operational philosophies (Stroul, 1988):

- Human dignity is primary. Individuals with mental illness are first and foremost persons with basic human needs, aspirations, desires, and feelings. The dignity and privacy of persons with mental illness must be respected.
- The value of fostering growth, improvement, and movement toward independence for individuals rather than dependence and "chronic patienthood" is critically important.



- The community is the best place for providing long-term care. Inpatient care is only to be used for short-term evaluation and stabilization, with only a small percentage of people needing long-term hospitalization.

The community support system philosophy is further embodied in the following principles (Stroul, 1988).

- *Services should be consumer-centered.* They should be based on and responsive to the needs of the consumer

rather than the needs of the system or the needs of providers.

- *Services should empower consumers.* They should incorporate consumer self-help approaches and should be provided in a manner that allows consumers to retain the fullest possible control over their own lives. Consumers also should be actively involved in all aspects of planning and delivery of services.

- *Services should be racially and culturally appropriate.* They should be avail-

able, accessible, and acceptable to members of racial and ethnic minority groups and women.

- *Services should be flexible.* They should be available whenever they are needed and for as long as they are needed. They should be provided in a variety of ways, with individuals able to move in and out of the system as their needs change.

- *Services should focus on strengths.* They should build upon the assets and strengths of consumers in order to help them maintain a sense of identity, dignity, and self-esteem.

- *Services should be normalized and incorporate natural supports.* They should be offered in the least restrictive, most natural setting possible. Consumers should be encouraged to use the natural supports in the community and should be urged to participate in the living, working, learning and leisure time activities of the community.

- *Services should meet special needs.* They should be adapted to meet the needs of subgroups of persons with severe mental illness who are members of minority and ethnic racial groups, elderly individuals and people with multiple disabilities.

- *Service systems should be accountable.* Providers should be accountable to the users of the services and monitored by the state to assure quality of care and continued relevance to consumer needs. Primary consumers and families should be involved in planning, implementing, monitoring and evaluating services.

- *Services should be coordinated.* They should be coordinated through mandates or written agreements that require ongoing communication and linkages between participating agencies and various levels of government. Coordination must occur at the consumer, community, and state levels. Mechanisms should be in place to ensure continuity of care and coordination between hospital and other community services.

These principles have been promoted and practiced for 15 years, creating a new model from which there is no turning back. As Anthony has stated in *Rehabilitation of Persons with Long-Term*



People with mental illness must be afforded respect for their rights, personal values and choices. (Photo, courtesy of Green Door, by Kris Ruckdeschel.)



*Mental Illness in the 1990's*, "Consumers and family members have entered the arena and demanded to play a role in treatment. The psychiatric rehabilitation field has moved inexorably toward acknowledging this role." Clearly, the key to designing and implementing services that are acceptable and work for consumers is to listen to the consumer of the service (Anthony, 1988).

As psychiatric rehabilitation moves toward the year 2000, philosophies and practices continue to evolve. While the guiding principles of the Community Support System still serve as a strong foundation for the development of mental health services, certain elements have emerged as equally important.

***In the treatment setting, to the extent possible, consumers should set their own goals and decide what services they will receive.***

- *Hope and Recovery.* Unquestionably, consumers want to be offered the hope that they will recover. Every individual with mental illness must be offered a vision of hope and possible recovery, even while recognizing that the need for community-based supports may be lifelong for some.

- *Safety.* Every consumer needs to feel safe both in treatment settings and in their home and community. This safety is much more than being safe from abuse and neglect: it is also feeling secure that your choices will be respected and your individual rights will not be taken away.

Each person needs a safe place of their own. This is not to suggest that everyone must have ownership of a place; rather it means that everyone should have a safe space in which they can live and be free of intrusion. The freedom of choice of where to live, what to do, and what mental health services to choose and accept should rest with the consumer to the greatest extent possible. The basic feeling of safety creates a solid foundation from which any individual can learn, grow and live to his or her fullest potential.

- *Rights, Respect and Dignity.* People with mental illness must be afforded respect for their rights, personal values and choices. Whatever their disability, they are to be treated equally and guaranteed the full protection of their legal rights. Even those with severe mental illness are full and equal citizens under the law and are entitled to equal access to the same opportunities, rights, services, supports, privileges, and responsibilities afforded all members of society (National Association of Protection and Advocacy Systems, 1994).

- *Empowerment.* In the treatment setting, to the extent possible, consumers should set their own goals and decide what services they will receive. Consumers should unquestionably be more and more involved in operating consumer-run programs and as service providers at all levels of treatment and rehabilitation. They must be accepted as copartners in service provision. New career paths must be established that place value on the experience of people who have lived with severe mental illness. Mental health programs should take advantage of the knowledge, experiences and empathy of persons who have been "in the system."

At the services level, consumers should be actively involved in planning and policymaking, and included on all relevant committees, boards and councils. Planners, providers, and administrators should dialog with consumers and respond to their stated needs and concerns.

***Every consumer has the right to live a fully integrated life in the community and to work in a chosen job.***

- *Community Integration and Employment.* Participation in community life is essential. Every consumer has the right to live a fully integrated life in the community and to work in a chosen job. Service providers and policymakers need to acknowledge the principle that people with mental illness can and do live meaningful and productive lives and should be given every opportunity to do so.

- *Families as a Key Resource.* Families are often the most important resource and support for individuals with mental illness and should be involved, wherever appropriate, in mental health services planning, policy development, delivery, monitoring, and evaluation. Families are big stakeholders in the manner in which mental health services are operated. While informed consumers are increasingly the best source of opinions about treatment options (which are often consistent as a whole with family wishes), consumers and families working together, rather than individually, can more dynamically impact the mental health delivery system.

- *Cultural Sensitivity.* Mechanisms to assure provision of acceptable and workable services include the use of culturally appropriate needs assessment tools; relevant quality assurance indicators; alternative service delivery models; engagement of neighborhood support systems; adequate representation on advisory boards, planning councils and program planning committees; cross-cultural train-




ing for staff; and use of indigenous workers and lingually fluent staff with cultural sensitivities.

- *Responsiveness of Services.* Services should be flexible, available and accessible to all. The rights, wishes and needs of primary and secondary (family members) consumers are equally important in planning and operating the mental health system. Mental health providers and consumers can in partnership develop and operate services that are comprehensive and coordinated, encompassing a range of options and resources from which the consumer can choose. Services should be individualized and provided in a manner that enables consumers to retain the fullest possible control over their own lives, while at the same time drawing upon the knowledge and experience of mental health providers. For the majority of individuals, the community is the best place for providing services.

## Vision

As psychiatric rehabilitation moves toward the year 2000, a world is envisioned in which consumers, families, and providers are working together to ensure that persons with severe mental illness:

- have a place to live, which they chose, in a community they prefer;
- are provided the supports and services they want;
- have available health and mental healthcare that is affordable and effective;
- achieve their maximum potential and live independently;
- are employed and fully integrated into community life;
- are respected, and treated with equity and fairness; and
- receive equal protection of their legal and human rights.

This is our vision and our challenge—together we can make it so. 

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# The Job Coach Network:

## A Successful Resource for the Supported Employment Work Force

***This article describes the Job Coach Network—an intervention used to address typical work related issues which often result in feelings of isolation and frustration and in high turnover for supported employment job coaches. The Job Coach Network was developed in 1988 in conjunction with a joint venture of the New Jersey Divisions of Mental Health and Hospitals and Vocational Rehabilitation Services to develop supported employment opportunities for individuals experiencing mental illness. The network, which continues today, uses peer support and problem solving, as well as formal and informal training to promote skill development, knowledge acquisition, information sharing, job satisfaction, and professional networking.***

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Approaches to promote integrated employment for people diagnosed with severe mental illness have received significant attention during the last 10 years. Beginning in the mid- to late eighties, an increasing number of articles appeared in the literature discussing supported and transitional employment. An entire issue of the *Psychosocial Rehabilitation Journal* was dedicated to supported employment in 1987. Anthony, Blanch, Danley, Bonds, and others discussed the roots of supported employment for people diagnosed with severe mental illness, the similarities and differences between supported employment for people with mental illness and for those with developmental disabilities, and

future directions in supported employment. Danley, Anthony, MacDonald-Wilson, and Mancuso described a comprehensive approach to integrated employment in the choose-get-keep model (Danley & Anthony, 1987; MacDonald-Wilson, Mancuso, Danley, & Anthony, 1989). A review of the first 10 years of supported employment as an employment approach was discussed by Isbister in 1990.

Findings have begun to emerge that more specifically discuss the efficacy of supported employment for people with mental illness and the learnings gleaned from comprehensive evaluations (Fishbein, Minsky, & Knepp, 1990). There are also descriptions of exemplary programs (Dalton, 1992). Less evident in the general supported employment literature are references to the human resource development dimension—the knowledge, attitude, and

skills needed by staff carrying out supported employment programs.

Moon and Stern have reported on a process to identify the staff development and technical assistance needed to prepare personnel at the preservice, inservice, and technical assistance levels to staff supported employment programs (Barcus, Griffin, Mank, Rhodes, & Moon, Eds., 1988). Inge, Barcus, and Evanson have discussed developing inservice training programs for supported employment personnel (Wehman & Moon, Eds., 1988). Kieger and Sales have written about the lack of qualified personnel for supported employment and have offered a design for preservice programs to address this need. (Wehman & Mood, Eds., 1988). More recently, McDonald and her colleagues have written and field tested a competency based training manual for job coaches (DiLeo, Ed., 1992). The manual covers a wide range of topics needed by a job coach in the field, including career planning, job development and marketing, arranging benefits, and supporting persons with a diversity of needs.

While these references focus on the implications of supported employment in assisting the consumer and preparing the system, programs, and personnel, nothing has been written about the

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human resource needs of staff in sustaining their efforts on behalf of the consumers they serve; and although much has been discussed related to the supports consumers need to enter and remain in employment, little has focused on supporting the staff who provide these supports. This article highlights some of the difficulties faced by job coaches or employment specialists in carrying out their functions and describes a unique and successful method of supporting these staff.

## Background

In the early spring of 1988, a joint venture of the New Jersey Divisions of Mental Health and Hospitals and Vocational Rehabilitation Services was undertaken to explore the efficacy of supported employment as a viable outcome for consumers. Resources from both agencies were utilized to establish contracts with four community mental health organizations who would develop countywide supported employment services targeted for consumers. The agencies selected for this first attempt had demonstrated competence in providing a range of vocational services but, because of the lack of resources, did not have the capacity to provide the intensive and extensive levels of support that are the hallmark and promise of supported employment. The initial efforts proved highly successful, starting with 4 countywide programs and expanding to 16 over the past 6 years, collectively serving over 1,000 consumers, and assisting more than 600 people into a range of integrated employment opportunities.

To promote the development of these first projects, an organizational meeting was held among the administrators, supervisors, and job coaches of the four community providers and representatives of the two state agencies to identify those systemic, programmatic, and personnel implementation issues that might impact on the ability of the new supported employment programs to provide quality services to consumers.

Many issues were identified and discussed at the meeting, including inter-

agency collaboration, reporting requirements, and other program implementation issues. One of the most important issues to emerge, however, was the unique role of the job coach in the mental health agency. Based on their brief experiences in this role, the job coaches identified the challenges inherent in their duties and what they believed their individual needs would be.

Some issues were readily apparent, such as:

- the isolation of working in the community, away from the facility;
- the need for a new and varied set of skills;
- the absence of peer support from coworkers who did not always understand the nature of job coaching; and
- the diminished availability of supervisors, as job coaches spend more of their time in the community.

Because isolation from peers, untested and unknown skills, and diminished supervisory support are highly correlated with professional burnout and often result in staff turnover, these were of great concern in the newly evolving programs. The importance of professional support has been discussed by others: "...the social and emotional support provided by peers can be critical for survival on the job" (Maslach, 1982, p. 111). Maslach goes on to suggest that during stressful periods, supportive coworkers provide things such as comfort and emotional support, insight by way of a different perspective, increased knowledge through the sharing of experience, and recognition for a job well done (1982). The job coaches found themselves in a true dilemma. They clearly needed support but were also pioneers in roles in which the mental health field had no experience. While their need for support was high, their coworkers and even supervisors had little experience to offer them regarding their tasks, duties, and functions. The formal and informal interactions with coworkers would be minimal at best, and there was already more confusion and, in some cases, resentment than empathy expressed by coworkers. The Job Coach Network was formed in direct response to the recog-

nition of the need for and lack of available assistance.

## The Intervention

An organizational network meeting for job coaches, coordinated by the authors, was scheduled. At that meeting, the group decided that the network job coaches would meet quarterly in a confidential place to air the frustration, impatience, disappointment, and confusion inherent in developing a new service while also developing needed skills. The primary purposes for launching the network was to provide the opportunity for job coaches to give and receive support from their peers, to identify issues, and to engage in problem solving. The meetings, which have also been used as formal and informal training sessions on topics of concern to members, typically open with a review of agenda items and a review of relevant statewide supported employment information. This is usually followed by a discussion of issues and specific difficulties experienced by job coaches in their respective agencies, and then by a brainstorming of possible strategies and solutions. Training on new information, methods, and technology, based upon prior requests, may also be presented. The authors have acted as facilitators by coordinating the meeting announcements and agenda development during the network's formative stages. However the group is self-directive, built upon a peer, mutual support, and empowerment model.

Over the past 5 years, network members have struggled with a variety of issues, some of which were directly related to doing the essential functions of job coaching, such as developing activities which help people with limited knowledge of the world of work, to choose what they want to do, forging new or different relationships with coworkers, other providers, VR counselors, and the business community; developing marketing skills and materials that address the specific needs of each group of customers; providing for the changing support needs of the supported employees; and facilitating



coworkers' understanding of the nature of supported employment and the role of the job coach. Some issues were related to the support needs of the job coaches: facing rejection from employers, dealing with the frustration and disappointment when a job match doesn't work out, accepting coworkers' taunts about the perceived laziness of job coaches because they were more out of the facility than in, and staying focused on supported employment while being pulled in many directions by their agencies.

Some issues seem to pose philosophical dilemmas, such as: deciding between helping someone get a first job or helping someone else who has lost or left a job to get another; striving to remain non-exclusionary in service entry criteria while the number of consumers awaiting supported employment service grows exponentially; and recognizing the importance of helping people achieve their life dreams while working in a system that often considers those life dreams "unrealistic." Finally, there were concerns expressed about the ability of the system to enable competent job coaches to remain on the job. Also, based upon experiences of job coaches serving persons with developmental disabilities, there seemed to be high turnover among their peers across the country, as the vocation is often entry level with low pay, non-clinical in nature, lacking in career advancement opportunities within supported employment, and, therefore, low in status—factors which often made job coaches feel devalued in their mental health agencies.

While answers to all of these issues and questions were not always forthcoming, the Job Coach Network was having a significant positive impact on acknowledging the problems and searching for answers. The issues raised were meaningful to all of the participants, and discussions about the issues were not merely complaint sessions but involved brainstorming and problem solving. Training needs were identified and met in timely way. Most telling of all, network meetings were attended with remarkable regularity by job

coaches whose schedules were routinely full and varied.

This past winter, as the group approached its fifth anniversary, the authors decided to evaluate what had been observed over the course of the group's evolution: that the network has reduced job coach isolation and increased professional connection, skills information sharing, and overall satisfaction.

A mail survey of members was conducted concerning the special features of the Job Coach Network. Included were questions about job tenure, ways in which the network helped in providing services, and what personal benefits were noted by members. The results, which were tabulated using a simple frequency of response, are highlighted below.

Thirty-seven percent of those responding had been members of the network for 3 to 4.5 years, 16 percent had been members for 1-2 years, and 47 percent were members less than 1 year at the time of the survey. (It is important to note that 6 of the 16 supported employment programs had been in operation for less than 1 year at this time.)

Job coaches reported that the network has helped them in the following ways:

- Seventy-nine percent said it helped with support.
- Seventy-nine percent reported it helped with training.
- One hundred percent related that it helped with information sharing.
- Fifty-eight percent indicated it helped with problem solving.
- Thirty-seven percent said it helped with job satisfaction.
- Sixty-eight percent reported it helped with issue identification/clarification.
- Thirty-seven percent stated it helped with intervention with their employer.
- Twenty-one percent said it helped with intervention with funding source.
- Sixty-eight percent reported that it helped as a resource for knowledge, technology, and research findings.

In response to the question, "What network benefits would you identify?" job coaches responded as follows:

- Eighty-four percent reported a decrease in feelings of isolation in their role.

- Ninety percent described an increased feeling of self-worth.

- Ninety percent told of an increased feeling of competence in their role.

- Seventy-four percent reported enhanced professional networking.

- Ninety percent related they felt better about the value of the job coach's role.

- Eighty-four percent described increased feelings of connectedness to their colleagues.

When asked "Has membership in the network influenced your decision/ability to continue in the job? If so, how?" 53 percent of the total respondents said yes, and 60 percent of the job coaches who were in their jobs for 1 year or more also answered affirmatively.

Specific comments from the survey included:

"Many network members feel similarly to me; hearing their stories has made me feel good about where I work and what I do."

"It has made my job easier; sharing ideas and hearing other coaches' difficulties."

"It has enriched my job."

"The group's input has made difficult days easier and decreased my feelings of isolation."

"It has helped me to see that my skills will increase with time."

"It provides support and information sharing."

"It gives me a break from a job which can be overwhelming."

When asked "How has membership in the network effected your feeling about the role of job coach?" members responded:

"It has shown me the importance of our role to consumers and to the field."

"It has given me support when I felt my agency neglected to." "It lets me know I'm doing a good job."

"It gives me a chance to see how others feel about the role."

"It has made me more aware of what I should be doing."

Coaches added additional information in response to the question, "Are there other benefits of the Job Coach Network?"

"Networking with peers and colleagues and information sharing promotes a feeling of professionalism."



"It has enabled a consumer I work with to make contact with another person with similar interests."


"It aids the learning process for job coaches and leads to feelings of connectedness."

"It gives me a chance to get away from my regular routine."

## Discussion

Clearly, the job coaches' responses confirm the network as a valuable and effective resource. The survey results indicate that this form of work force support has real potential in influencing job retention, continuing education, and continuous quality improvement. The success of a network for job coaches who work with consumers has led to the creation of a network for coaches working with individuals with developmental disabilities in New Jersey.

Supported employment programs, as with most human service functions, are highly labor intensive. Typically, 85 percent of organizational budgets are dedicated to personnel. The effect of staff turnover in continual recruitment, retraining, and time spent in job acclimation is costly to the organization, to the individual staff person, and, most

importantly, to the consumer served by the organization. The development of a job coach network is a work force intervention that is cost effective, easily replicated, and successful. The return on the investment in starting a network is clear. The increased satisfaction and effectiveness of staff can only have a positive effect on consumer success and satisfaction in gaining integrated employment opportunities. 

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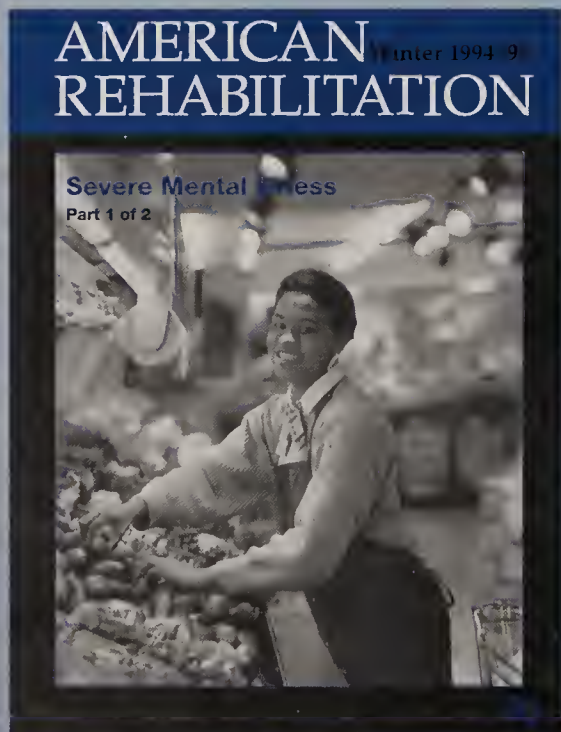
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# Rehabilitation of People with Severe Mental Disorders: Lessons from Healthcare Reform

Cille Kennedy, Ph.D.

## Rehabilitation Methodology

As with physically-caused disabilities, rehabilitation of adults with mental disorders can be viewed in three ways: *improving existing skills* that have diminished; *compensating for lost skills* that are permanently lost; and *learning new skills* that would have ordinarily been learned during the stage of life when the person was experiencing the disorder. For example, a person distracted by hallucinations may need rehabilitation in order to *improve* concentration and organization to prepare a meal that is well-balanced and cooked

in such a way that all the component parts can be served in the proper order. Another person, disabled by a physical disorder, may also need rehabilitation in food preparation, once all the necessary assistive devices are in place, in order to *improve* use of the devices to facilitate meal preparation. Both persons are receiving rehabilitation in food preparation, an instrumental activity of daily living (IADL).

A person disabled by a mental disorder for full-time work as an executive assistant who, because of hallucinations, can no longer concentrate sufficiently to carry out complex assignments may receive rehabilitation to become a part-time cashier in a thrift shop. A person disabled by a physical

condition—such as a leg amputation—who can no longer work as a lumberjack, may be rehabilitated to acquire the necessary skills related to a sedentary job. In both cases, these skills *compensate* for abilities that are permanently lost.

Instances of people who utilize rehabilitation to gain skills not learned since the onset of the disorder both for people with physically-related and people with mentally-related disabilities would be those who could not develop the range of age-appropriate social skills. There is an old story about a boy who was diagnosed with a serious heart condition and told to remain in bed rest. Many years later, as a man, he was told his condition was ameliorated and he could resume a normal life style. He is said to have responded: "I can't! I don't know how to dance!" Recreation and the associated social skills are part of a normal life. People experiencing a long-term episode of mental disorders during late adolescence may not acquire age-appropriate social skills during that time. When the episode clears, they may use rehabilitation to learn and practice skills that will assist engaging in fulfilling relations with their peers.

To summarize, this opening intends to make two main points. First, rehabilitation serves at least three purposes: improving diminished skills, compensating for lost skills, and learning skills that were not learned. Second, rehabilitation for people disabled by mental disorders

***The specific inclusion of rehabilitation as a covered service under long-term care benefits in recent federal healthcare reform bills served to endorse rehabilitation as a necessary component of an integrated healthcare system. It also highlighted both the similarities and uniqueness of disabilities, thus the need for an array of services for people with severe physical and mental disorders. These similarities and distinctions also required thoughtful planning for implementation in terms of equivalent eligibility criteria for long-term care benefits for people severely disabled by their disorders. While no federal health reform bill was enacted, the issues raised continue to have impact on thought and planning for healthcare services. One example of this impact is the recent proposal to reconfigure the state service system for people with severe mental disorders on Medicaid in rehabilitation-oriented New York State (Foderaro, 1994).***

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is virtually the same as for those with other disabilities in its goals (e.g., maximum autonomy with maximum quality of life) and the overarching skills that need rehabilitation (e.g., meal preparation, use of a stove), although the techniques vary (e.g., use of assistive devices for cooking vs. proper sequencing and timing of food preparation).

***Rehabilitation for adults with mental disorders has been categorized in various ways.***

## **Rehabilitation of the Disabilities of Adults with Mental Disorders**

Rehabilitation for adults with mental disorders has been categorized in various ways. An article in preparation by staff of the World Health Organization (WHO) Division of Mental Health classifies rehabilitation of people with mental disorders as psychosocial rehabilitation (Üstün et al.). This manuscript explicitly states that rehabilitation is targeted at the *consequences* of disorder. Programs in rehabilitation include activities of daily living (ADL's), independent living skills training, vocational rehabilitation, and social skills training. In a recent unpublished review of the research literature on outcome assessment for people with severe mental disorders, commissioned by the National Institute of Mental Health (NIMH), Cook organizes the review into three categories of rehabilitation: vocational rehabilitation; residential rehabilitation; and social skills training (1992).

In apparent contradiction to the opening statements about the similarities between the mind and body in terms of rehabilitation, the above labeling of the categories of rehabilitation for people with mental disorders may imply a dif-

ference in rehabilitation for people with mentally-based vs. physically-based disorders. This is not the case. Mental disorders characteristically are associated with certain disabilities and physical disorders with others. For both groups, however, the characteristic disabilities are not unique to the disorder. For example, to know a person's disability does not necessarily inform the observer what disorder is the cause. Knowing that a person has limited mobility and may be incapable of walking does not tell you whether the cause is spinal cord injury or catatonic schizophrenia. A person may experience a "disability bed day," spending the day in bed because of the effects of hypothyroidism or depression. Knowing that a person has a certain disability does not convey the cause of the disability. The converse is also true: knowing a person's disorder does not necessarily predict the person's disability.

In many of the major national surveys, disability caused by severe conditions is assessed by ADL's. ADL's are mostly reflected in questions about the ability of an individual to use the toilet, attend to one's hygiene, and get out of bed. Clearly, no civilized society would condone a situation where a person is left to lie in bed without the capacity to get to the toilet. Yet, this is not the situation—for the most part—in which the disabilities of persons with severe mental disorders are manifest. As a generalization, adults disabled as the consequence of a severe physical disorder, once out of bed, toiletted, bathed and dressed, are capable of preparing meals, shopping, paying bills, taking medications, and socializing when the appropriate assistive devices are in place. In general, this is not true of people disabled by severe mental disorders: they are capable of getting out of bed, toileting, bathing, and dressing themselves (although perhaps at the margin of normative standards). Severe mental disorders characteristically result in decrements in social relations, work, recreation, appropriate behavior, and IADL's. IADL's include such activities as housekeeping, food preparation, use of transportation, medication management,

and budgeting. While these activities may not initially appear to be as basic to daily life as ADL's, the characteristic activities affected in people with severe mental disorders are fundamental to community life outside an institution.

## **Rehabilitation and Reforming Healthcare**

Understanding the similarities and distinctions between rehabilitation for adults disabled by mental and physical disorders was stimulated in the planning for federal healthcare reform. The Administration's now defunct Health Security Act planned to cover rehabilitation (and habilitation) for people with disabilities under the Long-Term Care benefits. According to staff of the Congress' Office of Technology Assessment (OTA), the intent of the Administration's healthcare plan was to provide services to the very needy, the most disabled among the population, in order to keep them out of institutions and in the community. People less severely disabled but still in need of care to remain in the community will continue to receive services under the auspices of state programs and under existing financial arrangements such as Medicare, Medicaid, and private disability insurance plans.

Although no longer under Congressional consideration, the Administration's Health Security Act continues at the federal level as the basis for future planning and as the underpinning of a study being conducted by the Congress' OTA. For the above stated reasons, it is worth reviewing the definitions of disability in the former Senate Bill 1757, which reflected the Health Security Act, and examining the issues they raise.

### **Senate Bill 1757**

Section 2103 of the Senate bill defined people with disabilities as:

"(1) INDIVIDUALS REQUIRING HELP WITH ACTIVITIES OF DAILY LIVING.—An individual of any age who—

(A) requires hands-on or standby assistance, supervision, or cueing [sic] . . . to perform three or more activities of



daily living [i.e., eating, toileting, dressing, transferring, bathing (§ 2103(c))], and

(B) is expected to require such assistance, supervision, or cueing [sic] over a period of at least 100 days.

(2) INDIVIDUALS WITH SEVERE COGNITIVE OR MENTAL IMPAIRMENT.—An individual of any age—

(A) whose score, on a standard mental status protocol (or protocols) appropriate for measuring the individual's particular condition specified by the Secretary, indicates either severe cognitive impairment or severe mental impairment, or both;

(B) who—

(i) requires hands-on or standby assistance, supervision, or cueing [sic] with one or more activities of daily living,

(ii) requires hands-on or standby assistance, supervision, or cuing with at least such instrumental activity (or activities) of daily living related to cognitive or mental impairment as the Secretary specifies, or

(iii) displays symptoms of one or more serious behavioral problems (that is on a list of such problems specified by the Secretary) which create a need for supervision to prevent harm to self or others; and

(C) whose [sic] is expected to meet the requirements of subparagraphs (A) and (B) over a period of at least 100 days."

The bill went on to define individuals disabled by severe or profound mental retardation and severely disabled children. Cognitive impairment in the context of this bill was understood to mean delirium and/or dementia, according to staff of the Department of Health and Human Services (DHHS). The above definitions raise at least five issues for continued consideration.

First, the definition for individuals requiring help with ADL's does not specify that the individual have a health condition. While it is difficult to imagine that the inability to eat, toilet, bath, dress, or transfer might be caused by anything other than a health condition, perhaps the following hypothetical example of a person from a less industrialized and less technological culture

will help. This person may have other means of eating (i.e., other than with forks, spoons, or chopsticks), different types of clothing (e.g., loin cloths), and alternative means of disposing of human waste materials than our toilets. In our society, the person would not be performing these activities according to our cultural norms and might possibly need hands-on or standby assistance, supervision, or cueing to do so but would not be classified as disabled.

Outrageous as the above example is, the lack of a statement about the disability being associated with a health related condition in this definition becomes startling in juxtaposition to the second definition for people with severe cognitive or mental impairment. This definition requires not only that a mental or cognitive impairment exist but that it be rated as severe on a standard protocol as well. No requirements for documentation of a physical disorder are mentioned in any definition of disability in the bill. Clearly, consequent regulations or administrative procedures to implement this definition would have assured that the lack of ADL skills is related to a health condition.

Second, a severe disorder or severe impairment does not necessarily lead to a disability requiring rehabilitation. For example, a person may have a severe case of pneumonia. Once recovered, the person should have no remaining disabilities. During the course of the illness, the person will be in bed (a disability bed day) and most likely not bathe or dress. For those days the person would be considered disabled, but this "disability" would neither last beyond the episode of illness nor require rehabilitation. An individual diagnosed with a Brief Psychotic Disorder (DSM-IV, 1994), a severe mental disorder identified by either having delusions, hallucinations, disorganized speech, or grossly disorganized or catatonic behavior lasting between 1 day and 1 month, will have a full return to his/her premorbid level of functioning. Again, as severe as the disorder itself is, the disabilities resulting from the disorder and experienced during the episode may also be se-

vere but not outlast the episode and not require rehabilitation.

Third, if disabilities can be viewed hierarchically, then deficiencies in ADL's and IADL's may be considered the most severe. It must be assumed that it is the severity of the disability that is truly important here, not the severity of the disorder. The disability, not the disorder itself, will be addressed by rehabilitation. The fact that the legislation requires a 100-day period as a minimum projection for the length of the disability wisely precludes eligibility for people with severe disabilities that are short-lived and not in need of rehabilitation, as in the examples above.

Fourth, the differences between the two Senate Bill 1757 definitions do not intuitively appear to be equivalent. The first definition applies to people with physically-based disabilities as well as to people with mentally-based disabilities. The second applies only to those with mentally-based disabilities. In the first definition for persons requiring help with ADL's the criterion is solely based on disability (although, as noted above, it is assumed that a health condition is the source of disability), while the second definition for people with severe cognitive or mental impairment requires a combination of a measure of mental functioning and ADL or IADL. In the second definition neither the standard for the mental status measure nor the number of IADL's are set forth, creating two potential opportunities for inequity when the definition is put into operation. On the positive side, for people with severe impairment there is recognition that these are less likely to be limited in the area of ADL's and likely to be limited in IADL's. On the negative side, that there is no definition for IADL's in the bill as there is for ADL's, along with a referral to the Secretary for specification, additionally detracts from the input provided by the clinical/rehabilitation experts who drafted the long-term care benefit and defers to policymakers for detail.

The bill reflects the perspective that IADL's might be considered higher in the hierarchy of disabilities. That is, they may be considered less severe than



ADL's. Thus, those with deficits in IADL's might be inappropriately provided benefits without an additional screen to assure equivalency. Furthermore, a frequency count of IADL disabilities would not necessarily appropriately reflect the severity of disablement as does a frequency count of ADL's. This section of the definition stands as an example that the Health Security Act was intended as an overarching plan with the details to be fleshed out.

**To date, there are no nationally generalizable empirical data on disability-based rehabilitation services.**

Finally, there is no definition of the term "impairment" in the bill. The term has both generic, everyday-use meaning as well as several taxonomic and federal program meanings. For example, impairment can be commonly used to mean "limitation." The usage is best appreciated in the DSM-IV instructions for rating Global Assessment of Functioning Scale that state: "Do not include impairment in functioning due to physical (or environmental) limitations" (p. 32). Hence, the term "functional impairment" (i.e., functional limitation) enjoys widespread use in the United States synonymously with "disability" and includes ADL's and IADL's. In addition, the WHO's *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH) defines impairment thus:

"In the context of the health experience, an impairment is any loss or abnormality of psychological, physiological, or anatomical structure or function" (WHO, 1993, p. 47).


Furthermore, federal programs (which have 43 different definitions of

"disability" (Kemp, 1991; Weaver, 1991)) have other meanings attached to the term "impairment." For instance, the Social Security Administration's two disability programs (Social Security Disability Insurance and Supplemental Security Income) use "impairment" as a synonym for "disorder" (U.S. DHHS, 1992). It is assumed that this was the case in the bill.

Identification of the types of disabilities and the causes of disabilities have significance when planning services for people with both physical and mental disorders. More IADL-responsive rehabilitation services are required for people disabled by mental disorders and more ADL-responsive rehabilitation for those with physical disorders. To date, there are no nationally generalizable empirical data on disability-based rehabilitation services. Among other practical applications, research in this area would assist federal and other governmental and nongovernmental planners and policymakers to understand the implications for long-term care benefits as healthcare systems continue to evolve. Research is needed on the dynamics, process, outcome, organization, and cost-effectiveness of rehabilitation for people disabled by mental disorders and, comparably, for those with physical disorders. Among federal agencies, research support is available from the National Institute of Mental Health, the Center for Mental Health Services, the National Center for Medical Rehabilitation Research, and the National Institute on Disability and Rehabilitation Research to investigate such rehabilitation issues.

## Conclusion

Recent federal activities for reforming healthcare and the national interest they continue to engender support the significance of rehabilitation as an integral part of the healthcare system, notably for people with severe mental disorders. Planning activities intended to implement the eligibility criteria for the long-term care benefits in healthcare reform also highlighted many conceptual issues regarding disablement.

What also becomes apparent in view of these activities is that there is a paucity of research to provide an empirical base for both the projections of the diverse array of people eligible for rehabilitation services and an understanding of the dynamics, structure, and financing of cost-effective rehabilitation within the existing healthcare system for people with severe disabilities resulting from physical and/or mental disorders. 

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# NEW PUBLICATIONS AND FILMS

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## **Working on the Dream. A Guide to Career Planning and Job Success.**

*Don Lavin and Andrea Everett, writers. Beth DePoint, editor and producer. Rise, Incorporated, 8406 Sunset Road Northeast, Spring Lake Park, MN 55432-1387. 136 pages. Softcover, \$15 plus \$3 postage and handling.*

This publication is a self-administered, step-by-step career planning guide for people with mental health disabilities in their pursuit of meaningful employment. The publication not only gives a practical guide to understanding ADA and how this landmark legislation impacts employability, but will help people identify job preferences, marketable talents, and employment barriers through structured planning activities. Most importantly, the book encourages people to implement plans to realize their career goals.

The authors believe that people with disabilities need to learn how to take charge of their job futures and that by becoming more actively involved in choosing a career path, identifying specific personal goals, organizing community service plans, developing partnerships with employers and service providers, and learning techniques of self-management and advocacy, people can be more successful in their chosen careers.

*Working on the Dream* guides the reader through important career planning issues and poses major questions he or she will need to answer to secure, keep, and succeed at the job of his or her choice. Questions are specific to job interests, skills, talents, education, training, wage needs, transportation options, disability barriers, communication skills, and other em-

ployment-related factors. The goal of this particular exercise is to help the reader write a career plan which can serve as a useful blueprint.

The book also features detailed instructions and samples to help the reader put together an effective resume as well as cover letters and other correspondence with employers.

It offers suggestions about creative problem solving and provides real-life examples about how others have successfully removed obstacles on their path to job success. Case studies demonstrate how people have successfully arranged job accommodations with their employers and have developed creative solutions which reduce the effects of their mental illness symptoms in the workplace.

This publication provides practical insights about how mental illness symptoms can be managed effectively in the workplace through careful personal assessment, creative planning, and arranging for essential job supports.

Although this book is intended for use by people with mental health disabilities, they are encouraged to talk to vocational rehabilitation counselors, mental health professionals, therapists, employers, and family members about their job goals and employment search. Some may choose to develop and follow career plans independently, others may choose to seek assistance from a service agency.

Regardless, the basic premise of this publication is that each person needs to become actively involved in determining the amount and type of support needed to choose, find, and keep a job in the community.

## **Evaluation and Treatment of the Psychogeriatric Patient.**

*Diane Gibson, editor. The Haworth Press, Inc., 10 Alice Street, Binghamton, NY 13904-1580. 111 pages. Hardcover, \$22.95.*

Designed to assist occupational therapists and other health providers in developing up-to-date psychogeriatric programs and understanding details of treating cognitively impaired elderly persons, this book emphasizes the expertise of leading psychogeriatric occupational therapists, focusing on transitional programming, treating cognitive deficits, and recognizing the malignant cultural myths which continue to disenfranchise and denigrate elderly people.

## **Occupational Therapy and Psychosocial Dysfunction.**

*Susan Cook Merrill, editor. The Haworth Press, Inc., 10 Alice Street, Binghamton, NY 13904-1580. 237 pages. Hardcover, \$37.95; softcover, \$19.95.*

This text provides a comprehensive view of occupational therapy practice in psychosocial dysfunction. It emphasizes case studies for discussion and descriptions of programs and specific treatment activities that provide students with concrete ideas to try, as well as theoretical rationale underlying those treatment activities. Contributors to this text share programmatic ideas and communication about day-to-day treatment and assessment methods. Some of the strategies introduced by this guide include an intervention based on a model of human occupation and object relations theory, use of a group process to enable patients to regain control of their lives, treatment strategies based on neurocognitive



deficits, a neurophysiological model of schizophrenia etiology, and leadership therapy. Chapters deal with special timely issues such as eating disorders, chemical dependency, combat-related PTSD, and survivors of sexual abuse.

**Recovery from Schizophrenia.  
Psychiatry and Political Economy.  
Second Edition.**

Richard Warner. Routledge, 29 West 35 Street, New York, NY 10001. 366 pages. Hardcover, \$69.95; softcover, \$25.00.

The first edition of *Recovery from Schizophrenia* was acclaimed on publication as a work of major importance. It demonstrated convincingly, but controversially, how political, economic, and labor market forces shape social responses to the mentally ill, mold psychiatric treatment philosophy, and influence the onset and course of one of the most common forms of mental illness. In this revised and fully updated edition, Dr. Warner analyzes the latest research to refine the argument in his original book and to give new answers to such questions as, "Has industrial development affected the number of people who develop schizophrenia?" and "How may we create opportunities for the economic advancement of mentally ill persons?"

The opening chapters of the book establish the background for the subsequent analysis. The first chapter outlines what is known about the factors that promote the appearance of schizophrenia and that shape the course of the illness. The material is presented in such a way that readers who are not already familiar with the facts and features of the illness will learn enough to understand the rest of the book. The next chapter provides details of the ways in which mental and physical health are influenced by the economy, by social class and by the conditions of labor.

The middle section of the book looks at the impact of political economy on schizophrenia. Chapter 3 is an analysis of outcome studies of schizophrenia since the turn of the century and tries to establish whether changes in the long-term course of the illness are linked to large-scale fluctuations in the economy.

The extent to which political, economic, and labor market forces shaped the postwar policy of deinstitutionalization is examined in Chapter 4; and the role of similar forces in the development of institutions for the insane in the eighteenth and nineteenth centuries and in molding the treatment philosophy of the period is discussed in the following chapter.

Chapter 6 looks at possible reasons for the link between the economy and outcome from schizophrenia and Chapter 7 attempts to explain why schizophrenia is a less malignant condition in the Third World. The plight of the Western schizophrenic person and the way in which the social role and alienation of the psychotic person shape the course of the illness are examined in Chapter 8. Moving from the course of schizophrenia to its incidence, Chapter 9 analyzes how economic development, social stratification, and birth complications influence the appearance of the illness.

The final section deals with treatment issues. Chapter 10 evaluates the limitations of the antipsychotic drugs and the place of low-dose and drug-free treatment. The importance of work, economic opportunities, consumer involvement, and community support in the management of psychosis is covered in the final two chapters.

**Psychological Stress in the Workplace.**

Terry A. Beehr. Routledge, 29 West 35 Street, New York, NY 10001. 258 pages. Hardcover, \$49.95.

This book identifies the sources, consequences, and treatments of stress in the workplace from the perspective of organizational psychology and makes clear recommendations for future work in this area.

The author discusses how role ambiguity and conflict act as stressors in the workplace and how the characteristics of the job and organization itself can adversely affect performance. He examines the effects of stress in the workplace and describes methods that can be used to alleviate the problem, both at the individual and organizational level.

**Psychoanalytic Therapy in the  
Hospital Setting.**

Paul Jaussen. Routledge, 29 West 35 Street, New York, NY 10001. 229 pages. Hardcover, \$65.00; softcover, \$19.95.

The author describes the different models of inpatient therapy which have been tried and evaluated and explains his own integrative model in detail, illustrating it with clinical vignettes. He also shows that inpatient groups are particularly effective in the treatment of severe personality disorders, borderline conditions, and psychosomatic illness.

**Key Words in Psychosocial  
Rehabilitation.**

Myron G. Eisenberg, editor. Springer Publishing Company, 536 Broadway, New York, NY 10012. 116 pages. Softcover, \$23.95.

Using a selection of words and concepts from a review of 150 publications on psychosocial rehabilitation, the author presents this guide to the current use of key words in the field. This guidebook should help to clarify and standardize terms that may be confusing or ambiguous. This volume also includes an *Epilogue on Professional Client Communication in Rehabilitation Practice*.

**Accepting Disability.**

Hoyt Anderson. Successful Living Press, P.O. Box 163656, Sacramento, CA 95816. 164 pages. Softcover, \$9.95.

An examination of how persons with disabilities can cope with their physical limitations, this book is intended as a guide to enable persons with disabilities to develop positive self-esteem and to reach their fullest potential. It is the author's contention that, whether they believe it or not, the vast majority of disabled Americans today have psychological problems. The author challenges people with disabilities to set goals, then offers advice on how to reach these objectives, and provides the reader with ways to relate to others, thereby to become a happier and more productive individual.



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# AMERICAN Spring 1995 REHABILITATION

## **Severe Mental Illness**

**Part 2 of 2**





# *RSA's Commitment to Services for Persons Who Have Severe Mental Illness*



*Commissioner Fredric K. Schroeder*

In recent years, the Rehabilitation Services Administration (RSA) has sponsored a number of activities to support the work of state vocational rehabilitation (VR) agencies in the vocational rehabilitation of individuals who have severe mental illness.

RSA funded an evaluation study, entitled *Best Practice Study of Vocational Rehabilitation Services to Severely Mentally Ill Persons*, completed in 1989 by Policy Studies Associates. Based on information collected from state VR and mental health (MH) agencies, from samples of local VR and MH staff in 10 states, and from VR consumer case records in 6 of these states, the study summarized find-

ings on barriers to employment outcomes and strategies found to be effective in helping individuals who have severe mental illness to improve their vocational status.

Based on recommendations of the National Task Force on Rehabilitation and Employment of People with Psychiatric Disabilities, RSA initiated a *Program Administrative Review on the Rehabilitation of Individuals with Severe Mental Illness* in 1992. This review followed up on the *Best Practice Study* by exploring the extent to which state VR agencies are implementing best practices and the extent to which use of best practices appears to be associated

with improved employment outcomes. Data was gathered during late 1993 and early 1994 and a report is expected during the summer of 1995.

For many years, RSA has funded a variety of demonstration and training projects related to individuals who have severe mental illness. Demonstration projects have covered a wide range of approaches to expanding employment opportunities. A number of projects have focused on supported and transitional employment for individuals who have severe mental illness, working to develop higher level placements, tailor job coaching and follow-along services to meet the needs of individuals who have severe mental illness, and testing the use of natural supports and intensive support services, especially those provided through psychosocial rehabilitation programs. Also funded were projects that adapted the provision of supported employment services to meet the special needs of individuals who have severe mental illness and mental retardation and of individuals who have severe mental illness and are deaf.

Demonstration projects provided opportunities to improve linkages with state VR agencies, psychosocial rehabilitation programs, and other community providers to enhance job development, placement, and support services for individuals who have severe mental illness. A similar set of projects focused on linkages between state VR agencies and consumer run programs.

A number of other field initiated projects include:

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# Achieving Reasonable Accommodation for Workers with Psychiatric Disabilities: *Understanding the Employer's Perspective*

*This article is intended to educate rehabilitation counselors about employers' concerns in accommodating workers with psychiatric disabilities. It identifies six reasons why employers might be hesitant to make reasonable accommodations, reviews relevant guidance from the Americans with Disabilities Act (ADA) and its accompanying regulations, and proposes constructive approaches that rehabilitation counselors and mental health consumers can take in response.*

Laura L. Mancuso, M.S., CRC

**T**he employment provisions of ADA have now been in effect for almost 3 years. Among the many important aspects of the law for workers with psychiatric disabilities is the requirement that employers provide reasonable accommodation.

Although the ADA's wording on reasonable accommodation closely follows the regulations for Section 504 of the Rehabilitation Act of 1973, the new law has a much broader reach. All employers with 15 or more workers are now covered. Many employers—particularly small businesses—have never previously been subject to laws prohibiting discrimination on the basis of disability. They may be unclear about the extent of their obligations or apprehensive about the potential impact of the law on the operation of the business.

Employers are particularly concerned about how to accommodate workers with psychiatric disabilities. This is often identified as one of the more challenging aspects of ADA implementation. Statistics show that 11 percent of claims under Title I to date nationally have been filed by people identifying themselves as having emotional or psychiatric impairments, comprising the third leading category of claimants.<sup>1</sup> Although the situation has improved in recent years, technical assistance materials on reasonable accommodations have historically offered little guidance for employers in this area, focusing instead on workplace modifications for employees with mobility, hearing, or visual impairments.<sup>2</sup>

Although most workers with psychiatric disabilities will never need reasonable accommodation, rehabilitation

counselors are likely to be called upon to assist those who do. Since ADA's enactment, rehabilitation counselors have been identified as a logical source of information and assistance to employers. There are several reasons: first, rehabilitation counselors are unique among human service professionals in their focus on serving people with disabilities; second, the field has always encompassed vocational issues; and finally, rehabilitation counselors are trained to perform job analyses and functional assessments, both of which are very useful in developing workplace accommodations.

Whether they consider their customers to be mental health consumers, employers, or both, rehabilitation counselors are well-positioned to assist in the development of workplace accommodations. However, those practitioners who primarily serve people with other types of disabilities may feel unprepared to assist individuals with psychiatric disabilities. Likewise, psychiatric rehabilitation specialists may be knowledgeable about the concerns of mental health consumers but less familiar with the issues of the business workplace.

This article provides information for rehabilitation counselors to use in supporting a person with a psychiatric disability who needs and wants a workplace accommodation, but has encountered obstacles to obtaining it. The article is organized around six questions that rehabilitation counselors and their clients should consider when negotiating reasonable accommodations. Consideration of the questions will elicit an understanding of potential barriers to accommodation from the employer's perspective. Each question is followed by a discussion of relevant guidance from the ADA statute or its



regulations and constructive approaches to addressing the employer's concerns. The questions were derived from the author's experience in delivering training to diverse audiences on ADA implementation for workers with psychiatric disabilities.

The strategies presented here are designed to be cooperative, rather than coercive. While there are many excellent printed resources for people with disabilities on how to initiate legal action, such as filing a complaint with the U.S. Equal Employment Opportunity Commission (EEOC)<sup>3</sup>, advice on alternative approaches to resolving ADA disputes is less readily available. This should not be construed as an attempt to deter mental health consumers from seeking legal redress when discrimination has occurred, because there are many instances in which that is the best and most appropriate course of action. But there are also many instances where reasonable accommodations are best pursued by other means. This article offers an alternative to a more contentious rights enforcement approach. Just as it would be unethical for a rehabilitation counselor to discourage a mental health consumer from pursuing legal remedies in the face of discrimination, it is equally short-sighted to prematurely rule out more cooperative methods which might bring greater benefits to the client in the near or long term.

1. *Is the employee covered by ADA?* One of the first questions that rehabilitation counselors and their clients should consider is whether the employer believes that the individual requesting an accommodation is covered by ADA. People with only a superficial knowledge of ADA are often not aware that the law covers individuals with substantially limiting *mental* impairments. This can be true of people who run businesses; depending on the size and nature of the business, there may be dozens or even hundreds of new county, state, and federal mandates each year relevant to their industry.<sup>4</sup> For rehabilitation counselors, on the other hand, ADA may well be the single most significant legislation in decades. Unlike most employers—es-



pecially small businesses—they are likely to have immersed themselves in studying the implications of the law through publications, professional conferences, and the day-to-day practice of their trade.

If an employer is not aware that the ADA definition of disability includes individuals with mental impairments, it may be helpful to offer written information, such as the EEOC free booklet, *The Americans with Disabilities Act: Your Responsibilities as an Employer*.<sup>5</sup> Cornell University's Program on Employment and Disability has also published a useful four-page brochure, *Employing and Accommodating Workers with Psychiatric Disabilities*, which offers a basic introduction to the topic.<sup>6</sup>

Difficulties also arise from a difference of opinion between the employer and the employee about whether an individual's mental health problem is substantial enough to constitute a disability under the law. The ADA definition requires that the mental impairment impose substantial limitation in the performance of one or more major life activities. People with temporary disabilities (whether physical or mental in nature) are generally not covered. However, a severe impairment that may be long-term or indefinite in duration qualifies as a disability under

the law. Not everyone, then, with a mental health problem—or even a DSM-IV diagnosis—is “an individual with a disability” under the law. This has led to confusion among employers, who are often unclear about what legally constitutes a disability resulting from a mental impairment.<sup>7</sup>

Based on their experience with the explosion of stress-related claims for Workers' Compensation over the past decade, some employers have become suspicious of people who claim to have a mental disorder. Recent articles in business periodicals have suggested that, as further restrictions are imposed on stress claims, there will be a trend toward increased claims under Title I of ADA.<sup>8</sup> The simple fact that people with psychiatric disabilities—like those with

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*Ms. Mancuso is an independent consultant and trainer residing in Goleta, California. Since ADA's enactment, she has delivered training on the implications of the law for workers with psychiatric disabilities to over 5,000 business representatives, mental health consumers, and professionals in mental health and rehabilitation. She is Senior Consultant to the Washington Business Group on Health and works as a Psychiatric Rehabilitation Specialist with the County Mental Health Services in Santa Barbara, California.*



epilepsy, heart disease, and diabetes, for example—do not typically appear to be disabled may lead employers to question accommodation requests and/or to ask for verification of the disability.

Rehabilitation counselors may not be aware that ADA gives employers the right to request written documentation of an employee's disability when he or she requests an accommodation. In fact, EEOC's ADA technical assistance manual indicates that rehabilitation counselors may be among those called upon to furnish the documentation.<sup>9</sup> When providing such reports, rehabilitation counselors should keep in mind that the objective is to confirm that the need for accommodation stems from a disability-related functional limitation: there is no provision permitting the employer to obtain, for example, a complete psychiatric history or a treatment plan. Therefore, the information released should be restricted only to that needed to substantiate the functional limitation. Of course, rehabilitation counselors should follow standard procedures for obtaining written consent from the client for the release of information to a third party.

Ironically, because of an employee's excellent performance on the job an employer may not be convinced that the worker requesting an accommodation actually has a disability. Some people with psychiatric disabilities summon vast amounts of energy to perform well from 9 to 5, only to return home exhausted. They may spend their evenings or weekends recuperating, even hospitalized, but still maintain the appearance of effortless excellence in the workplace. When they request an accommodation, their supervisors may be surprised, noting that they don't seem disabled. If the mental health consumer's own statements are not sufficient to convince the employer that he/she has a disability, the worker may need to obtain a brief, written statement from a rehabilitation counselor or other health professional substantiating the need for the accommodation.

2. *Has an effective accommodation been identified?* Another potential obstacle to achieving accommodation is the

identification of an effective workplace modification. Employers are often uncertain about how to develop accommodations for people with psychiatric disabilities. For example, a recent article in *The Wall Street Journal* stated, "...accommodating the mentally ill isn't simple. It's one thing to provide for someone in a wheelchair, but quite another to manage an employee with mood swings, phobias, or trouble dealing with others."<sup>10</sup> There is convincing evidence that Americans, in general, are less comfortable dealing with people with mental illness in any context than they are in meeting people with other types of disabilities.<sup>11</sup> The development of accommodations is also complicated by the fact that changes are often needed in the intangible aspects of the workplace, such as schedules, work assignments, or supervisory methods. But changes to the physical environment may also be requested (such as the positioning of furniture, the location of an office, or the purchase of specialized equipment).

Companies have traditionally relied upon physicians for advice about work-related medical problems, and may turn to them for recommendations about accommodations. However, physicians—even psychiatrists—are not necessarily well-prepared to propose workplace accommodations for people with psychiatric disabilities, unless they have specialized in this area. Physicians are likely to recommend a course of action based solely on the individual's clinical symptoms, without assessing the client's skills and abilities, reviewing the job description, or visiting the worksite. All too often, no one involved has asked the one person who may be most qualified to propose an effective accommodation: the worker with the disability.

Rehabilitation counselors are uniquely qualified to assist in identifying effective accommodations. Their education prepares them to compare job demands with workers' abilities. In addition, the rehabilitation literature offers a plentiful supply of useful resource materials. For example, the continuing education home-study course offered by Direc-

tions in Rehabilitation Counseling on *Understanding the ADA* features a lesson on "Accommodations for Workers with Psychiatric Disabilities."<sup>12</sup> Rehabilitation professionals can also link employers and employees with technical assistance resources such as the Employer's Resource Center on the ADA and Workers with Psychiatric Disabilities at the Washington Business Group on Health<sup>13</sup> or the Job Accommodation Network.<sup>14</sup>

3. *Does the accommodation impose an undue hardship?* ADA requires employers to make accommodations for qualified workers with disabilities unless doing so would impose an undue hardship. The precise definition of "undue hardship" in the individual case is central to the issue of whether or not a particular accommodation must be made. Sometimes the employer perceives that the requested accommodation imposes an undue hardship while the employee does not. In fact, this is a frequent source of disagreement between the employer and employee in ADA-related disputes. Cumulative statistics on complaints filed with the EEOC since Title I's effective date document that "failure to provide reasonable accommodation" is the second most frequently cited type of discrimination (surpassed only by complaints of unlawful discharge).<sup>15</sup>

Rehabilitation counselors should consider the perspectives of both the employer and the employee in negotiating reasonable accommodations. For example, a person with a disability may express frustration because the employer is unwilling to make an accommodation that involves little or no immediate cash outlay. But reasonable accommodations for workers with psychiatric disabilities often involve changes in "the way things are customarily done."<sup>16</sup> Change, in most organizations, is very difficult for reasons having little to do with direct financial cost. It may be easier for a supervisor to secure a purchase order for the acquisition of assistive technology than to modify established practices. When an employer is unwilling to make a needed accommodation, consider the effect of the proposed change on the pro-



ductivity of the employee's work group, department, or division. Although beneficial for the rehabilitation client, a proposed accommodation might cause substantial disruption to others in the workplace. The rehabilitation counselor can help the worker with a disability generate additional options that will be effective for him or her while also minimizing any negative effect on overall workplace productivity. This is consistent with the process for developing accommodations detailed in the Title I regulations, which specify that the employer has "the ultimate discretion to choose between effective accommodations, and may choose the less expensive accommodation or the accommodation that is easier... to provide."<sup>17</sup> By increasing the number of options, rehabilitation counselors can strengthen the possibility of securing a reasonable accommodation.

While the regulatory definition of undue hardship includes the impact of the accommodation on the ability of other employees to perform their duties,<sup>18</sup> it specifically excludes consideration of disruption due to prejudice.<sup>19</sup> Similarly, the negative impact of an accommodation on the morale of other employees does not constitute undue hardship.<sup>20</sup> This is a particularly significant issue for workers with psychiatric disabilities, since prejudice against them is so common and since so often the workplace modifications they request are attractive to other employees. Because their disabilities are not typically apparent, coworkers sometimes presume that people with psychiatric disabilities are feigning illness in order to gain "special treatment." A recent article in the magazine of the Society for Human Resource Management commented that "Workplace attitudes are the most common barriers to accommodating employees with mental illness. The accommodations necessary for these disabilities have a larger impact on coworkers than accommodations for other types of disabilities and can cause coworker resentment." The authors suggest that educating coworkers about mental illness may lead them to be more "flexible about their own role in job sharing and other

accommodations"<sup>21</sup> for workers with psychiatric disabilities.

In the end, ADA requires employers to bear some expense or disruption in order to provide equal employment opportunities to people with disabilities. But they do not have to incur *undue* hardship, even if the worker with a disability requires the accommodation in order to effectively perform the essential functions of the job. Rehabilitation counselors can help negotiate a win-win situation, giving both the employer and employee something they need and want.

4. *Will other employees be informed about the accommodation? If so, how?* In ADA training sessions, employers frequently ask for advice on how to handle a confidential request for an accommodation. If an employee with a psychiatric disability has requested an accommodation that can be implemented without involving coworkers and is not otherwise apparent to others in the workplace, the employer can simply honor the request for confidentiality. However, in certain situations it is inevitable that others will become aware of the change. For example, if it is unusual for an entry-level employee to be assigned an enclosed office, coworkers are likely to inquire about why an employee was shown this apparent favoritism. Similarly, if a worker with a psychiatric disability requests a flexible schedule, this may impose certain demands on other workers to cover his or her duties. If others are not aware that the employee requesting the accommodation has a disability, the supervisor might well be uncertain about how to proceed.

There is little guidance for employers in this area. ADA specifies that information obtained from an employee's medical examination or inquiry must be kept in a confidential medical record separate from general personnel files.<sup>22</sup> However, the law does provide for the notification of managers and supervisors about any restrictions on the employee's duties and for safety personnel to be notified if emergency treatment is likely to be required.<sup>23</sup> These provisions imply that the employer

should, in general, respect the employee's confidentiality, but they do not attempt to address the nuances of workplace relationships.

From a practical perspective, when a worker with a non-apparent disability who also requests confidentiality receives an accommodation that others can observe, some negative repercussions are probably unavoidable. Imagine a situation where other employees inquire about the reason for a change and the supervisor is able to offer no comment. Whatever explanation he or she gives—or does not give—is open to misinterpretation in some way, even if it is only an uninformative statement that the reason for the change is confidential and will not be discussed. It is usually helpful to reassure the inquiring colleague that, should they make a request for confidentiality in the future, it will receive the same respect. Nonetheless, the absence of an official explanation often leads coworkers to their own conjectures regarding the accommodation and the tight-lipped response of the supervisor. Some workers with psychiatric disabilities report that the backlash from the "rumor mill" has been more damaging than a public announcement of their disability.

When the accommodation is clearly apparent to other workers, the person with a disability may choose to discuss with his or her supervisor how inquiries should be handled. They may jointly decide, for example, that a supervisor's statement that the change was made on the basis of a medical condition is appropriate with no further comment. Alternatively, the supervisor could refer all inquiries to the worker himself or herself. A somewhat more proactive approach, chosen by some rehabilitation clients, is to acquire permission from the supervisor to address a staff meeting at which the worker with a disability describes the arrangement and the reasons for it in his or her own words. In this way, the implementation of an accommodation can become an opportunity to educate people in the work environment about the personal experience of mental illness and about ADA.



Since anyone can become disabled at any time, this should be of interest to all employees. As one advocate commented, "The ADA provides an opportunity for employers to offer disability awareness training to all workers. This type of training could actually prevent jealousy or antagonism from erupting while de-mystifying important issues of people with disabilities. The larger effect of such training can be the reduction of stigma in the larger community."<sup>24</sup>

Rehabilitation counselors should know that some employers fear that making one accommodation will unleash an avalanche of requests by other workers that cannot be approved. This is more of an issue if the worker with a disability has requested complete confidentiality. If the person with a disability agrees that the supervisor may attribute the accommodation to a medical condition or disability, this becomes an excellent opportunity to reinforce the company's policy on making accommodations for people with disabilities. Regardless of how uncomfortable this situation is for the employer, however, he or she must make reasonable accommodations for qualified individuals with disabilities, and respect the employee's confidentiality in doing so. Given the potential consequences, decisions about whether or not to disclose in the workplace, what to say, when, and to whom, should always be made by the individual with a disability.<sup>25</sup>

5. *Does the supervisor have the authority to make the accommodation?* A supervisor who appears unwilling to make a needed accommodation may actually lack the authority to make such a change. The approval process may be very time-consuming and the supervisor may be reluctant to undertake it. For example, the proposed change may conflict with the terms of a collective bargaining agreement. Employers have been given little guidance in this area; the Appendix to the Title I regulations indicates that the terms of a collective bargaining agreement "may be relevant" but apparently not determinative to the assessment of undue hardship.<sup>26</sup> Inter-

estingly, both the employer and the union are generally covered by ADA.

If the supervisor does not appear to have the authority to make a proposed accommodation, it may be helpful to involve other relevant contacts from within the organization, such as the Employee Assistance Program, or the Human Resources Department. More and more large and medium-sized companies are also designating Ombudsmen<sup>27</sup> [sic] who can help mediate employee requests and complaints; they may be able to recommend effective approaches to achieving reasonable accommodations within the company's unique culture and structure. They may also act as an internal advocate, working with the supervisor to accommodate the needs of the employee with a disability. Corporate disability benefits managers may also be able to intervene, particularly if the employee is receiving short-or long-term disability benefits and an accommodation could assist him or her to return to work.

***When negotiating an accommodation, it is important to realize that the fear of workplace violence may undermine the process.***

The company as a whole is responsible for making accommodations for qualified employees unless doing so would impose undue hardship. When trying to arrange accommodations, it is important to intervene at the right level in the organization (i.e., with someone who has the authority to make the change). Depending on the client's preferences, the role of the rehabilitation professional may be either to support him or her in this task or to communicate directly with the supervisor or other employer representative.

6. *Is there a fear factor about employing people with psychiatric disabilities?* A sig-

nificant but rarely discussed concern among employers in the hiring and accommodation of people with psychiatric disabilities is the perceived relationship between violence and mental illness. When negotiating an accommodation, it is important to realize that the fear of workplace violence may undermine the process.

Many employers are deeply troubled by the recent increase in the rate of violent crime in the workplace. The U.S. Department of Labor now compiles statistics on both fatal and nonfatal violent incidents in the workplace. They estimate that approximately 1,100 people are victims of homicide on the job each year, while another 22,000 are seriously injured by acts of violence in the workplace.<sup>28</sup> Employers are required by law to maintain a safe workplace, and face inestimable liability if found to have failed to do so, whether the perpetrator was formerly a model employee or an individual never before associated with the workplace.

It is an unfortunate fact that efforts to explain and control workplace violence often reflect a tendency to automatically attribute antisocial and criminal behavior to people with psychiatric disabilities. For example, a recent text on the prevention of violence in the workplace warned employers to be alert to 10 risk factors associated with individuals who become violent, including psychosis, depression, and personality disorders.<sup>29</sup>

In fact, the relationship between mental illness and violence is poorly understood. For years, mental health advocates insisted that people with mental illness are no more likely to become violent than any other person. More recent research findings appear to contradict this position. A recent survey of a broad range of epidemiological studies found that anyone experiencing active psychotic symptoms was at increased risk of committing violent acts, whether or not they had any previous history of psychiatric treatment. This study concluded, however, that there was only an indirect relationship between mental illness and violence to the extent that people with a history of mental disorders are more likely to ex-



perience active psychotic symptoms in the future, and it found much stronger correlations between violence and other factors, such as alcohol or other drug abuse. The article also refuted the popular conception that most people with mental illness are dangerous, concluding that, "None of the data give any support to the sensationalized caricature of the mentally disordered served up by the media [or] the shunning of former patients by employers..."<sup>30</sup> Unfortunately, such findings are not widely disseminated and are easily overwhelmed by the daily barrage from the news and entertainment industry linking violence and mental illness. This widespread stigma undoubtedly leads to considerable employment discrimination, even among some employers who make a good faith effort to comply with ADA overall. As an attorney specializing in employment law recently commented, "There is a certain fear factor about the mentally ill."<sup>31</sup>

Once a causal relationship is assumed between mental illness and violence, the employer may choose to risk an ADA lawsuit by refusing to hire, retain, or accommodate someone known to be mentally unstable rather than to risk workplace violence. Of course, even if an employer could avoid hiring anyone who had ever received psychiatric treatment, the risk of on-the-job violence would not be removed. And the liability associated with violating ADA can be substantial, including compensatory and punitive damages.

For example, a school board in Oklahoma fired a speech pathologist when they learned that her recent hospitalization was due not to cancer but rather to an acute episode of bipolar disorder that had led her to believe she had cancer. Her job performance was satisfactory, as evidenced by the school's renewal of her contract. Two physicians certified that she was ready to return to work and was not a danger to herself or anyone else. She had never shown any tendencies toward violence. Nevertheless, the school board feared that she was dangerous and terminated her contract. An attorney representing the school district justified her dismissal:

"What position would the school district have been in if we let her go back to work and some of those students were injured or killed because of something she had done?" The teacher has filed a complaint under Title I.<sup>32</sup>

***Rehabilitation counselors should be aware of the fear factor and actively counter misinformation.***

The subject of workplace violence is inflammatory, controversial and little understood. Employers certainly need to provide a safe working environment. Unfortunately, some employers attempt to do this by keeping those people known to have mental illness out of the work force. Through its "direct threat" provision, ADA does provide employers with the right to disqualify from employment anyone who actually poses a significant risk of substantial harm in the workplace.<sup>33</sup> In this context, however, ADA's broader aim is to eliminate employment discrimination that is based on subjective impressions of the connection between mental illness with violence by requiring employers who use this provision to have objective evidence that the particular individual in question poses a significant risk of substantial harm to him/herself or others.<sup>34</sup> Rehabilitation counselors should be aware of the fear factor and actively counter misinformation. There are a number of approaches that can be used to counter it, including distributing written literature about mental illness, developing and delivering disability awareness training programs, and supporting the sharing of personal testimonials by people with psychiatric disabilities.

## **Conclusion**

The response of most employers to ADA is a constructive appreciation for its overall goals and thoughtful efforts

at compliance. The majority of companies are trying to do "the right thing." Some have even made the generation of employment opportunities for people with disabilities part of their mission. They have discovered that flexibility in accommodating the needs of the entire work force is a cost-effective way to do business. In these work settings, people with disabilities may secure the modifications they need without ever having them labelled as "reasonable accommodations."


But in other workplaces, any request for accommodation—even those that do not appear to impose undue hardship—may be denied. In a small number of cases, the employer may intentionally be evading the law. Fortunately, it appears that such instances of intentional discrimination are rare. There are some cases where the requested accommodation may actually impose an undue hardship and may therefore not be required. In most cases, however, some mutually satisfactory arrangement can probably be negotiated. Doing so requires that rehabilitation counselors and their clients uncover employer objections and concerns that may be unspoken.

In their classic text on principled negotiation, *Getting to Yes: Negotiating Agreement Without Giving In*, the authors explain why it is so necessary to become educated about the perspective of the other party:

"The ability to see the situation as the other side sees it, as difficult as it may be, is one of the most important skills a negotiator can possess. It is not enough to know that they see things differently. If you want to influence them, you also need to understand empathetically the power of their point of view and to feel the emotional force with which they believe in it...be prepared to withhold judgement for a while as you "try on" their views. They may well believe that their views are "right" as strongly as you believe yours are."<sup>35</sup>

This article has investigated a number of reasons why employers might be hesitant to make accommodations and proposed steps to respond to their concerns. The questions considered here may help prepare rehabilitation



counselors to support or participate in the negotiation of reasonable workplace accommodations for people with psychiatric disabilities. More people with disabilities will achieve their rights under ADA by exploring a variety of approaches to securing them. 

## Notes

1. U.S. Equal Employment Opportunity Commission, Office of Program Operations, "Cumulative ADA Charge Data for July 26, 1992–December 31, 1994 Reporting Period," January 1995.

2. Mancuso, L. (1990). Reasonable Accommodation for Workers with Psychiatric Disabilities. *Psychosocial Rehabilitation Journal*, 14(2), 3–19.

3. Two publications by the EEOC may be useful: a booklet entitled, *The ADA: Your Employment Rights as an Individual with a Disability*, or the more comprehensive *Technical Assistance Manual on the Employment Provisions (Title I) of the ADA*. Each are available from the EEOC Publications Information Center (Telephone: 1–800–669–3362). Also, an excellent 40-page booklet entitled, *Mental Health Consumers in the Work Force: How the ADA Protects You Against Employment Discrimination*, is available from the Bazelon Center for Mental Health Law, 1101 15th Street NW, Suite 1212, Washington, DC 20005.

4. Keep in mind that employers may need to comply not only with ADA but also with Title V of the Rehabilitation Act of 1973 or state laws with similar nondiscrimination provisions which remain in effect. Similarly, the Family & Medical Leave Act (FMLA)—another statute which overlaps with yet differs from ADA—requires larger employers to provide unpaid leave to employees with "serious health conditions."

5. This booklet is also available from the EEOC Publications Information Center (1–800–669–3362).

6. To obtain the brochure, contact your Regional Disability and Business Technical Assistance Center (1–800–949–4232).

7. To help clarify the definition of "disability" the EEOC has issued a new section for its compliance manual,

which features many examples of workers with psychiatric disabilities. The 49-page document is called *Directives Transmittal Number 915.002, EEOC Compliance Manual Section 902, Definition of the Term "Disability"* (issued March 14, 1995). It is available from the U.S. EEOC's Office of Communications and Legislative Affairs at (202) 663–4900.

8. Mackey, A. (1994). Redressing Stress Without Workers' Comp. *California Lawyer*.

9. *A Technical Assistance Manual on the Employment Provisions (Title I) of the Americans with Disabilities Act*, U.S. Equal Employment Opportunity Commission, January 1992. Available from the EEOC Publication Center at 1–800–669–3362 (voice or TDD).

10. Harper, L. (1994, July 19). Mental-Health Law Protects Many People But Vexes Employers. *Wall Street Journal*, pp. A1, A5.

11. Taylor, H. and Wurf, N. (1991). *Public Attitudes Toward People with Disabilities*. Study No. 912028. New York: Louis Harris & Associates, Inc.

12. Available from Directions in Rehabilitation Counseling, 420 East 51st Street, New York, NY 10022. Telephone: 1–800–367–2550 (voice).

13. This project was funded by the National Institute on Disability and Rehabilitation Research to help employers comply with ADA as it applies to employees with psychiatric disabilities. For more information, call the Washington Business Group on Health at (202) 408–9320 (voice) or (202) 408–9333 (TDD).

14. The Job Accommodation Network, a service of the President's Committee on Employment of People with Disabilities, provides free telephone consultations on accommodating persons with disabilities in the workplace. Their telephone number is 1–800–ADA–WORK (voice/TDD).

15. U.S. Equal Opportunity Commission, Office of Program Operations, "Cumulative ADA Charge Data for July 26, 1992–December 31, 1994 Reporting Period," January 1995.

16. This is one definition of "reasonable accommodation" from the Appendix to 29 CFR 1630.2(o).

17. Appendix to 29 CFR 1630.9(a).

18. 29 CFR 1630.2(p)(2)(v).

19. Appendix to 29 CFR 1630.15(d).

20. Appendix to 29 CFR 1630.15(d).

21. Waert, L.V., and Dailey-Thomas, J. (1994, March). Mental Condition Does Not Excuse Misbehavior. *HRMagazine*, p. 55.

22. 42 U.S.C. 12112(c)(3)(B).

23. 42 U.S.C. 12112(d)(3)(B)(i)&(ii).

24. Personal communication, L. Van Tosh, October 13, 1994.

25. For further discussion about deliberations by individuals with nonapparent disabilities about disclosure on the job, see *Case Studies on Reasonable Accommodation for Workers with Psychiatric Disabilities* by L. Mancuso, (1993), available from the Washington Business Group on Health. Telephone: (202) 408–9320 (voice) or (202) 408–9333 (TDD).

26. Appendix to 29 CFR 1630.15(d).

27. Ombudsmen Proliferate in the Workplace. (1992, February 19). *Wall Street Journal*, p. B12.

28. "Violence in the Workplace Comes Under Closer Scrutiny," *Issues in Labor Statistics*, August 1994, Bureau of Labor Statistics, U.S. Department of Labor.

29. Baron, S.A. (1993). *Violence in the Workplace: A Prevention and Management Guide for Businesses*. Ventura, CA: Pathfinder Publishing of California.

30. Monahan, J. (1992). Mental Disorder and Violent Behavior: Perceptions and Evidence. *American Psychologists* 47(4), p. 519.

31. Comment by Attorney Michael Lotito as quoted in Woolse, C. (1994, June 27). Employers unsure of liability exposure from bias allegations by mentally disabled. *Business Insurance*, pp. 3–6.

32. Harper, L. (1994, July 19). Mental-Health Law Protects Many People But Vexes Employers. *Wall Street Journal*, pp. A1, A5.

33. 29 CFR §1630.2(r).

34. 29 CFR §1630.2(r).

35. Fisher, R., Ury, W., and Patton, B. (1991). *Getting to YES: Negotiating Agreement without Giving In—2nd Edition*. New York: Penguin Books, p. 23.



# Mental Illness and AIDS

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Previously, people with mental illness have been overlooked in the AIDS epidemic. Yet, despite long-held stereotypes, adults with mental illness—particularly those individuals who are homeless, have problems with drug and alcohol abuse, or lack the motivation to change self-defeating behaviors—are sexually active and engage in a range of sexual behaviors that put them at high risk for HIV (Cates, Bond, & Graham, 1994; Sacks, Silberstein, Weiler, & Perry, 1990). Recent surveys show that *persons with mental illness are one of the groups most imminently threatened by AIDS.*

National data are not available; however, since 1991 eight reports on HIV seroprevalence among people with serious mental illness in New York indicate rates ranging from 4.0 percent to as high as 22.9 percent (Satriano, Herman, Kaplan, & Cournos, 1994). One study, for instance, reports an infection rate of 19 percent for homeless, mentally ill men in a New York City shelter. This is almost twice the rate reported for men of a similar age in a representative community sample in central Harlem—an epicenter of AIDS (Susser, Valencia, & Torres, 1994).

For individuals who have been mentally ill since childhood or adolescence, normative psychosexual development may have been arrested so that they cannot maintain normal social and sexual relationships (Carmen & Brady, 1990). Sexual behaviors that place these individuals at high risk include: frequent anonymous sex, generalized hy-

***This article argues that people with mental illness are in need of both primary AIDS prevention education and secondary AIDS management education. People with mental illness are at an above average risk of being infected with HIV. Several factors associated with this increased risk are described.***

persexuality, tendency toward multiple sex partners, and decreased likelihood of using contraceptives, including condoms (Akhtar & Thomson, 1980; Cournos, Guido, Coomaraswamy, Meyer-Bahlburg, Sugden, & Horwath, 1994; Sacks, Dermatis, Burton, Hull, & Perry, 1994; Susser, et al., 1994).

Furthermore, there is a large crossover population of people with mental illness who are either homeless, are drug or alcohol abusers, or are poor, any of which *results in the exchange of sex for drugs.* Because of their impulsivity, hallucinations, lack of social skills, difficulty initiating contact or maintaining personal relationships, and problems with sexual aggression, these people are more at risk for AIDS than the general population (Brenda, 1991; Carmen & Brady, 1990; Susser, et al., 1994).

Factors that put individuals with mental illness at significantly higher risk for acquiring the HIV virus include:

- *Homelessness.* Homeless persons generally demonstrate inadequate relationship skills. In particular, women who are homeless are at risk of rape, sexual molestation, and sexual abuse, thus increasing their risks of being infected with the AIDS virus (Brenda, 1991). Many homeless men have histories of intravenous (IV) drug use and prison or jail experiences (Susser, et al., 1994).

- *Homosexuality or bisexuality.* This group of individuals with mental illness is not generally integrated into the gay community through which they could get access to education about AIDS (Carmen & Brady, 1990).

- *Childhood sexual abuse.* As part of the post-traumatic sequelae of such abuse, these people have low self-esteem and have been repeatedly victimized or engage in sexually promiscuous, impulsive, and dangerous behaviors (Carmen & Brady, 1990; Carmen & Rieker, 1989).

- *Dual diagnosis with co-occurring morbidities of substance abuse.* Regier and associates (1990) estimate that 30 percent of individuals with a lifetime prevalence of major mental illness have a co-occurring substance abuse disorder. Even if these persons do not directly inject drugs, the intoxicated state

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is frequently associated with poor judgement about sexual behavior (Carmen & Brady, 1990; Sacks, et al., 1994). For instance, the results from a survey of individuals with mental illness and chemical abuse (Hanson, Kramer, Gross, Quintana, Li, & Asher, 1992) reveal that 40 percent of these clients had multiple sex partners; 38 percent engaged in unprotected oral sex; 28 percent had sex with drug users; 22 percent had sex with prostitutes; 16 percent engaged in anal sex; and 12 percent traded sex for drugs.

## Need for Services

It is not surprising to find that people with mental illness lack the knowledge to choose low-risk behaviors. Of the 50 clients that Hanson and associates sampled (1992), 56 percent did not know that individuals infected with HIV may not look sick; 48 percent did not know how to clean their needles and syringes to reduce AIDS transmission; 70 percent believed that latex and natural condoms provide equal protection from the virus; 32 percent thought that Vaseline and baby oil are good to use with condoms (this may cause breakage); and 64 percent thought that a condom should fit tightly over the head of the penis (instead of leaving space at the tip). Furthermore, Aruffo, Cloverdale, Chacko, and Dworking (1990) found that despite a significant history of IV drug abuse, only 53 percent of female psychiatric outpatients (the majority of whom were sexually active) knew that condoms help prevent AIDS. Findings from these studies suggest the need for both basic HIV prevention information and intensive training.

Education about risk is fundamental to AIDS prevention efforts but by itself is usually insufficient to produce and sustain behavior change. Evaluations of AIDS-related behavior-change programs are consistent in their findings: the most effective prevention programs are tailored to the risk populations and their particular characteristics (Stover & Pequegnat, 1994).

Sometimes, characteristics of the specific mental illness, such as cognitive

impairment, poor judgement, affective instability, and impulsivity, engender the behaviors that put these persons at risk (Aruffo, et al., 1990; Carmen & Brady, 1990; Hanson, et al., 1992; Harvey & Trivelli, 1990). For example, persons in acute manic episodes are often hypersexual; whereas individuals in depressed stages may be sexually inactive and need a very different treatment approach (Carmen and Brady, 1990).

The following characteristics associated with long-term or chronic mental illness support the need for modified HIV education:

- People with mental illness may experience *greater than normal stress related to rejection, making decisions, or being alone* (Miller & Miller, 1991).

- Long-term mental illness may cause *difficulties in understanding reality, following complex directions, abstract thinking, decision making, solving simple problems, taking responsibility, and interpersonal processes* (Aruffo et al., 1990).

- People with long-term mental illness may have *problems initiating and completing tasks* due to cognitive difficulties or as a result of psychotropic medications (Region V Study Group, 1991).

- Chronic mental illness, including schizophrenia, may include *sexual dysfunctions, such as sexual fears, hallucinations, delusion, and wishes* (Akhtar & Thomson, 1980).

***The researchers recommended expanding their program to include education on sexual refusal assertion skills.***

AIDS prevention education specifically designed to meet the particular needs of persons diagnosed with mental illness has been minimal. Generally, AIDS education programs have focused largely on the general public and spe-

cific groups, such as gay men and IV drug users. Only a few projects have attempted to provide to individuals with mental illness information about sexuality, reducing high risk behaviors, or methods of handling the psychiatric symptoms and stresses that accompany the HIV virus or AIDS (Harvey & Trivelli, 1990).

The myths perpetuated by staff and institutions about the sexual behaviors of persons with mental illness may be one reason for the very low level of educational activity within this population. These myths include beliefs that persons with mental disabilities are oversexed, undersexed, or lack control; have diminished cognitive capacity to understand sexual behavior; are unable to use contraceptives; and are unable to be parents (Cook, Razzano, Jayaraj, Myers, Nathanson, Scott, & Stein, 1994). Others have expressed concern that discussing sex and drugs with people with mental illness may encourage sexual disinhibition and alcohol and drug use (Satriano, et al., 1994). As a result, there has been a lack of consensus regarding the need for sex or sexuality education and an absence of HIV prevention guidelines for this population (Harvey & Trivelli, 1990).

The AIDS prevention initiatives that have been targeted for individuals with mental illness refute assumptions that these persons are incapable of understanding or changing sexual behaviors. For example, Goisman, Kent, Montgomery, Cheevers, and Goldfinger (1991) presented HIV prevention materials in a clear, succinct, and repetitive manner with audiovisual aids to 50 schizophrenic outpatients. The information was given in three 1-hour sessions, 1 week apart. Initially, the clients who were at considerable risk of AIDS demonstrated denial of substance abuse and significant gaps in knowledge about AIDS. However, 50 percent of the patients were asking for condoms and for more information 6 months following the course. The researchers recommended expanding their program to include education on sexual refusal assertion skills.



## Type of Needed Prevention Activities (primary education)

There is a strong need for both primary (preventive) and secondary (management of psychiatric symptoms) AIDS education for people with severe and persistent chronic mental illness across the country. "In the absence of vaccines or treatments that can prevent or cure AIDS, new infections can only be prevented by persuading people to lower or eliminate behaviors that put them at risk of receiving or transmitting the virus" (Stover & Pequegnat, 1994, p. 3).

Virtually all patients with mental illness may have heard about AIDS and are afraid of catching it; however, they do not have accurate information about the disease, or the information they do have is in a form that they cannot use (Carmen & Brady, 1990). In a survey of 265 outpatients, Zafrani and McLaughlin (1990) identified 56 who were most at risk of contracting AIDS, based upon sexual and/or drug activities. These outpatients scored lower than other patients in knowledge of AIDS. Similarly, Sacks and associates (1990) indicated that 56 percent of persons in high risk groups were relatively unconcerned about becoming infected.

Education efforts should focus not only on the provision of information on the risks and consequences of AIDS, but also on a change in behaviors (Harvey & Trivelli, 1990). For example, in a study of 83 people with mental illness receiving partial hospitalization services, knowledge of HIV/AIDS was weakly correlated with frequency of at risk behaviors (Steiner, Lussier, & Rosenblatt, 1992). Since AIDS is a behaviorally transmitted disease, there is a need to encourage new behaviors that will reduce transmission.

The experience of rehabilitation providers and mental health care professionals indicates that systematic plans for instruction, motivation, and followup are necessary in order to adequately reduce risk to this population (Carmen & Brady, 1990; Kelly, 1991; Stover & Pequegnat, 1994).

***Behavioral change to reduce risk of AIDS is a slow and complex process even within a healthy population.***

For persons with long-term mental illness or dual diagnosis, HIV prevention materials are needed that include assertiveness training, group problem solving, conflict management training, training in ways to manage high risk situations, and explicit instruction in correct condom use (Hanson, et al., 1992). These needs go far beyond the typical HIV prevention information campaigns that are being undertaken currently (Carmen & Brady, 1990; Kelly, 1991).

Behavioral change to reduce risk of AIDS is a slow and complex process even within a healthy population (Carmen & Brady, 1990). For patients with mental illness, impulsivity, and severe disturbance of self-esteem may prevent compliance. However, there is evidence that low risk behaviors can be adopted to replace high risk behaviors after exposure to AIDS prevention (Carmen & Brady, 1990; Kelly, St. Lawrence, Hood, & Brasfield, 1989).

A three-step process has been shown effective in changing behaviors around the world among IV drug users (Des Jarlais & Friedman, 1988). The three principles of social learning—motivation, means of behavior change, and a means of reinforcement—can also serve as a framework for an AIDS prevention program for persons who are mentally ill.

First, HIV prevention programs should increase motivation to avoid high risk behaviors (Harvey & Trivelli, 1990). Developing motivation begins with an accurate assessment of individual risks. The practical importance of accurate AIDS information is that it allows individuals to assess their own personal risk and allows those with high risk behaviors the opportunity to

label such activity as problematic (Morin, 1988). These individuals then can change their behavior by themselves or seek the help of others in charge.

Second, providing the means for behavior change, such as clean needles for IV drug users or availability of free condoms, is critical. Low risk behaviors must be taught that can replace the high risk behaviors. Certainly, such practical skills as learning how to use a condom are very useful (Carmen & Brady, 1990). However, the central goal of all AIDS education programs is to teach people with mental disabilities how to establish realistic and sound attitudes about sexual relationships and personal activities and how to maintain a responsible sexual lifestyle that protects health and well-being (Harvey & Trivelli, 1990). To do this, it may be necessary to teach assertiveness and reasoning, decisionmaking, relationship, and negotiating skills (Harvey & Trivelli, 1990). In addition, there should be discussions of HIV testing that include indications for and consequences of such testing.

Third, these programs should reward behavior change by providing group or peer support for reduced risk conduct, assertiveness training, and reinforcement of alternatives to current high risk activities. These techniques have proven effective with other programs that change behaviors to prevent morbidity, such as weight reduction and cigarette cessation.

Part of the reinforcement for new behaviors which reduce the risk of AIDS may come from the decrease in the individual's fear that he/she will acquire the HIV infection. Reinforcement may also come from changed peer group standards or norms about the behavior. Des Jarlais & Friedman (1988) report that the strongest correlate of behavior change in the individual was whether that individual believed his or her friends all to be changing their behavior in response to AIDS. This suggests that educating peer groups together could be useful.



## Staff Education

It may be necessary to educate staff at the same time as or before clients enter an AIDS prevention program. There are several reasons for making this suggestion:

- Staff may blame patients for their high risk behavior or they may have incorrect assumptions about their capability to learn new materials, thus providing a significant institutional barrier.

- Staff themselves may need education concerning AIDS. It has been shown that an increase in knowledge about AIDS helped reduce healthcare workers' reported stress, perceived risks, and negative attitudes (Weinstein, 1990). Knowledge of many aspects of the lives of persons with HIV disease may also help alleviate fears associated with the treatment of homosexuals and IV drug users and may facilitate a higher level of comfort for those working with HIV-infected patients (Alford, Aruffo, Thompson, Dobbins, & Gottlieb, 1994; Duffy, 1994).

- Staff are needed to help identify client characteristics, needs, and scope of the educational program (Harvey & Trivelli, 1990).

It should be noted also that occupational stress among mental health workers is traditionally high (Jette, 1982). The negative effects of stress for the mental health staff can lead to less humane attitudes towards clients. Research demonstrates that the emotional stability and interpersonal behavior of caregivers can be critical in developing and maintaining an adequate recovery by psychiatrically impaired individuals (Baker, Kazarian, Helmes, Ruckman, & Tower, 1987). These findings indicate the importance of stress management education for mental health staff.

## Programs to Support HIV Individuals and Prevent Spread of AIDS (secondary education)

The AIDS virus may have its own distinctive psychiatric manifestations. The mental health problems resulting from AIDS-related central nervous system damage may include organic men-

tal syndromes, mood disorders, and suicide (Hurley & Ungvarski, 1994; Penner, 1994). The early organic mental changes may be subtle and can occur without concurrent systemic manifestation. These disorders manifest themselves through a variety of symptoms and do not progress at any predictable rate. Emotional, behavioral, or personality changes may be erroneously attributed to functional disorders and to the impact of living with an incurable, stigmatizing, and ultimately fatal infection rather than to central nervous system damage. Any of the organic mental syndromes can interfere with a patient's understanding and compliance with treatment. Recommended treatment strategies include psychoeducation, psychosocial support, assessment of suicidal risk, and pharmacotherapy (Aladjem, 1988).

Persons with mental illness who are HIV positive or have AIDS need supportive counseling, not only to educate them about the means to prevent the transmission of AIDS, but also to assure that they are able to handle the psychological manifestations and stresses of the illness. Behaviors primarily responsible for the transmission of HIV involve sex and drug use—activities that are strongly motivated, often well established, and highly reinforcing. For instance, the individual may be "using sexual relationships to validate his attractiveness and to relieve temporarily moments of despair that were worsened by alcohol" (Kelly, 1991). It is imperative, therefore, that HIV management involve the following components:

- intensive review of the specific circumstances surrounding recent occasions when risky activity occurred and when risk urges were strong, followed by determination of the skills the patient will need to handle the situation differently in the future;
- opportunity through role playing to practice declining sexual overtures assertively;
- guidance regarding how to avoid unnecessary rejection or to handle unavoidable rejection when it occurs;
- guidance regarding how to avoid situations associated with casual sex and

realizing "that brief encounters do not reduce the loneliness that triggers them when reaching for the first drink"; and

- understanding of the "cycle that will be fueled by alcohol-increased loneliness, decreased inhibition, hopelessness about long-term relationships, and a return to the same patterns again" (Kelly, 1991, p. 240).

Furthermore, in assessing the impact of AIDS on people with psychological and social problems manifested in mental illness, the predisposition toward being unable to cope successfully with external and internal pressure should be considered.

Testing positive for HIV—even without the presence of any physical symptoms—can be stressing even in a person who does not have previous mental illness. Some of the known stressors include feeling infectious, having to face death and dying, feeling ambivalent about the virus, utmost uncertainty about the future life course (e.g., what and when will they have AIDS-related diseases, how many years are left to live), desire to maintain secrecy, and lack of counseling related to HIV testing (Aladjem, 1988). The physical presence of AIDS causes additional psychological problems. The social stigma associated with AIDS, for instance, can lead to a lack of support systems, alienation, and total isolation.

***Stress management benefits mental and physical health as well as enhancing the immune system.***

The experience of being HIV positive or of having AIDS results in major psychosocial stressors that have the potential to exacerbate physical or psychiatric illness (Hurley & Ungvarski, 1994; Penner, 1994). Results of a 6-year study (Burack, 1991) indicate that HIV



positive men suffering from moderate to severe depression lose greater numbers of T-cells, tend to develop AIDS more quickly, and die sooner than their nondepressed counterparts. Relieving stressors has been found to increase the immune system and might forestall or eliminate the onset of disease complications (Antoni, Schneiderman, Fletcher, Goldstein, Ironson, & Lapperriere, 1990). Thus, stress management is an important part of mental health treatment.

Despite many special cognitive and affective learning deficits, severely psychiatrically disabled persons also have demonstrated that they can learn a wide variety of stress management skills (Brown, 1980; Liberman, 1982). Exercise, relaxation techniques (such as guided imagery), cognitive re-appraisal, and social support reduce the need to resort to substance abuse or acting out in response to stress (Ergi & Canton, 1982). Stress management benefits mental and physical health as well as enhancing the immune system.


## Conclusion

The current status of AIDS prevention education for persons with mental illness stands in sharp contrast to the increased need for such training. The framework for primary AIDS prevention education that is appropriate for this population involves the following:

- sharing information about the transmission of AIDS in order to motivate behavior change;
- providing the means to change behavior, such as building interpersonal assertiveness and relationship skills, or making condoms available; and
- providing means of reinforcement for behavior change.

To complete these goals, rehabilitation staff serving individuals with mental illness should receive education in order to dispel any false assumptions that they may have about the capacity of persons with mental illness to comprehend their risk of AIDS or to change their risk behaviors. In addition, AIDS education will lower staff

fears of and stresses from working with HIV+ individuals.

Finally, people with mental illness who are HIV+ or who have AIDS can benefit significantly from secondary AIDS management education. In an effort to reduce the transmission of the AIDS virus, these individuals need assistance to cope with the psychosocial stressors of having the disease. The pre-existing emotional, behavioral, and personality characteristics of mental illness are exacerbated by the psychiatric manifestations of AIDS. Treatment, therefore, should include education, psychosocial support, stress management, and appropriate pharmacotherapy. 

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# Encouraging Disclosure of Psychiatric Disability

## *mental health consumer and service provider perspectives on what employers can do*

**Consumers of mental health services have many concerns about disclosing psychiatric disabilities to employers and must weigh the advantages and disadvantages in deciding whether to disclose. To assist employers in creating open, accepting work environments necessary to encourage disclosure of psychiatric disability, a number of strategies available to consumers and to service providers of rehabilitation and supported employment programs are described herein.**

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Once the decision to disclose a psychiatric disability to a potential or current employer is made and careful consideration has been given concerning the benefits of disclosure, care must be taken to prepare the way to assure the most favorable environment for disclosure. To assist in the creation of the open climate necessary to encourage disclosure, consumers and service providers suggest a variety of

strategies for employers; in making their services available to employers, they can facilitate the development of an accepting workplace environment.

### Concerns About Disclosure

Many consumers are afraid of disclosing to an employer their experience with disabling mental illness (U.S. Congress, Office of Technology Assessment, 1994). Society, through television, movies, and other media, portrays people with mental illness negatively. Often, people mistakenly believe that people with mental illness are intellectually impaired and are unable to learn new skills and knowledge or are unable to work productively and contribute to society. Consequently, consumers are often afraid that if they disclose before employment they may not be hired or that if they disclose after they might either not be promoted or may even be terminated, in spite of protection under the Americans with Disabilities Act (ADA). Also, some consumers who have disclosed have experienced difficulty in receiving positive feedback from their supervisors: either the supervisor would only provide negative feedback—because the supervisor was trying to get rid of them—or the supervisor would be hesitant to provide any constructive criticism for fear of upsetting or hurting the feelings of the employee.

In balancing these negatives against disclosing, consumers and service providers also must consider some of the benefits. After disclosure, consumers are free to be themselves, relieved of much of the stress caused by concealing a significant part of themselves from their coworkers and supervisors. Without that added stress and with a sense of being accepted for

who they are, employees with psychiatric disabilities can be even more productive and better able to concentrate on their work. Finally, once the consumer has disclosed, he or she is able under ADA to request reasonable accommodations. Preliminary data from a supported employment program for people with psychiatric disabilities in Maryland indicate that consumers who disclose disability and request reasonable accommodations were employed for a longer period of time than those who did not disclose (Fabian, Waterworth & Ripke, 1993).

In deciding whether to disclose, there are several issues that consumers and providers must consider. Consumers and providers must assess the employer's attitude and openness and his/her experience employing people with psychiatric disabilities; the acceptance of coworkers; and the direct supervisor's experience with giving constructive feedback and his/her general management style. Once the decision to disclose is made, it is important to choose when and to whom to disclose. Consumers should be aware that under the law they can disclose at any time—before or during the initial interview, in followup interviews, after

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***Disclosing sooner rather than later increases the opportunities for developing an open, trusting relationship with the employer. . . .***

the job offer but before starting work, or at any time once employed. It is advised, however, that disclosure occur *before* serious performance problems arise on the job and also well in advance of disciplinary or termination procedures (U.S. Congress, Office of Technology Assessment, 1994). Disclosing sooner rather than later increases the opportunities for developing an open, trusting relationship with the employer and for identifying acceptable and reasonable accommodations.

## **Changes in Hiring**

There are a number of actions employers can take to encourage disclosure of psychiatric disability in the workplace and to create the open, accepting environment where consumers feel more comfortable about making the decision to disclose.

Employers can post policies regarding hiring people with disabilities in recruitment literature, job postings, and in Equal Employment Opportunity literature.

Statements regarding the company's willingness to make reasonable accommodations for applicant's disabilities in the application, testing, and interview process can be noted (Parrish, 1991, Zuckerman, Debenham & Moore, 1993). Employers can recruit from col-

leges, rehabilitation agencies, mental health agencies, vocational or technical training programs for people with disabilities, or from psychosocial rehabilitation programs.

Interviewers should be trained not only in the legal and illegal interview questions under ADA guidelines but also in how to sensitively respond to an applicant who does disclose a disability, intentionally or inadvertently. Expressing appreciation for the disclosure and focusing on the performance of the job tasks may help put the applicant at ease.

Finally, describing examples of some accommodations in the hiring process, specifically some that people with psychiatric disabilities might need, such as untimed tests, interview in a private office, accompaniment by a job coach (Zuckerman, et al., 1993; Parrish, 1991; Mancuso, 1993, 1990; Howie the Harp, 1992) may indicate to people with psychiatric disabilities that the employer is sensitive to their needs.

## **Changes On-The-Job**

In addition to the above, there are a number of strategies that employers can use in the on-the-job aspect of employment to create an accepting workplace culture.

Employers can develop or locate educational materials about reasonable accommodations, mental illness, the impact of mental illness in the workplace, and treatment and rehabilitation. Providing literature such as booklets on ADA and mental health consumers communicates an openness to employees about psychiatric disabilities (Mental Health Law Project, 1992). For example, Mt. Auburn Hospital in Cambridge, Massachusetts, has pamphlets on depression displayed outside the cafeteria alongside material on divorce, alcohol and drug abuse, and other topics. Educational materials can also be in the form of fact sheets posted in employee break rooms or available in human resource offices.

Articles can be written and published in employee newsletters. For example, Boeing Corporation has recently pub-

lished an article on depression in their employee newsletter.

Some employers are now also participating in National Depression Screening Day, held each October during Mental Illness Awareness Week (*Business & Health*, 1994a). Employers can notify employees about their participation in National Depression Screening in a number of ways: posting notices, sending memos, or including notes in employee paychecks. In 1993, 1,300 facilities in all 50 states screened 56,000 attendees. More than 50 percent scored positive for depression and were referred for outpatient treatment or hospitalization (B. Kopans, personal communication, August 1994). Companies can conduct an onsite screening or refer employees to local screening sites in the community.

Employers can also begin education and training programs for managers and employees. Training supervisors about various types of mental illness, potential signs of mental illness, how to deal with performance problems, how to identify reasonable accommodations, and how to identify resources available to assist employees with psychiatric disabilities is crucial.

First National Bank of Chicago teaches supervisors about the pervasiveness of mental illness and how it affects healthcare costs for the corporation (*Business & Health*, 1994b). First National Bank of Chicago gives pointers on how to recognize the symptoms of mental illness. The bank stresses that supervisors are taught to identify symptoms of mental illness but not to draw conclusions or attempt to diagnose or treat the employee. When supervisors recognize these patterns, they refer the employee to its Employee Assistance Program (EAP). The success of First Chicago's program is evident. In the past, almost all referrals to EAP were self-referrals. Now, about 40 percent of EAP referrals are coming from supervisors (*Business & Health*, 1994b).

NYNEX Corporation of Lowell, Massachusetts, has had a training program for employees as part of their Wellness Programs. This training seminar highlighted the symptoms of mental illness



and described reasonable accommodations and possible treatments. This seminar was in a series which included alcohol and drug abuse, as well as lectures on PMS, exercise, and other topics. The training program was given by a consumer-run center—the Mental Health Consumer Resource Center at McLean Hospital in Belmont, Massachusetts.

For employees with psychiatric disabilities who are having difficulty on the job, employers can consult with rehabilitation specialists knowledgeable about mental illness in the workplace. This employee-specific consultation can involve analyzing the technical and interpersonal demands of the job, assessing the implicit social and behavioral expectations of the specific job situation and the supervisory style used, evaluating the employee's functioning regarding these demands and skills, and recommending the skills to be developed in the employee, the supports or reasonable accommodations to be developed in the environment (physical, intellectual, and interpersonal), and the services needed to improve employee functioning. Describing the range of accommodations for psychiatric disability can best be found in other sources (Zuckerman, Debenham, & Moore, 1993; Parrish, 1991; Parrish & Mancuso, 1991; Mancuso, 1993, 1990; Parry, 1993), but often involve changes in supervisory strategies, communication, work schedules, and physical environment. Often, some of the accommodations are what any employee would want if he/she had a choice (e.g., an assigned parking space, a private office, balanced feedback from a supervisor). In these situations, the supervisor must be prepared to respond to the envious reactions of coworkers while still protecting the confidentiality of the employee with the psychiatric disability. Responses such as "We provide what our employees need in order to do their jobs well" communicates an employee-centered culture and may decrease resentment.

For employees who are returning to work from hospitalization or leave of absence after publicly "breaking down" on the job in front of other employees,

employers can ease that transition back to work by arranging for a mental health or rehabilitation professional to educate the other employees and respond to any questions or concerns. This is especially important if the employee with the psychiatric disability is a supervisor or an executive. For example, in a case study prepared by Julia Lieblich (1994), a chief of structure planning was hospitalized for manic-depressive illness. Prior to his return to work, it was recommended that a psychiatrist be made available to explain this illness to the other employees, in the hope that this would ease their emotional burden as well as the executive's upon his return.

***Employers can also be careful to choose health insurance plans that provide comparable coverage for mental health as for physical health.***

### **Changes in Benefits and Privileges**

Employers can also demonstrate their commitment to employing people with psychiatric disabilities by making changes in the benefits and privileges aspect of employment, such as by modifying their own EAP or contracting with an EAP that specializes in psychiatric disability and rehabilitation techniques for this disability. Educating employees about the availability of EAP and the types of assistance provided (referral, consultation, career counseling, individual therapy) is useful. Some companies have structured the EAP so

that the employees can use an EAP counselor as a behind-the-scenes support—someone safe to talk to when having a panic attack, someone to process angry feelings toward a coworker or supervisor, and/or someone to help employees develop skills around socializing and connecting with coworkers. Although these actual interactions may be relatively brief (15–30 minutes), they may occur periodically with the same EAP counselor and may operate contrary to the typical "consult-and-refer" approach. If this becomes too cumbersome for the EAP counselor to manage, he/she can refer the employee not only to therapy resources but also to professionals who specialize in employment and rehabilitation approaches, such as supported employment or psychiatric rehabilitation professionals. These specialists can specifically focus on the functioning-at-work aspects of the employee, rather than only on the medical or psychiatric condition and treatment.

Employers can also be careful to choose health insurance plans that provide comparable coverage for mental health as for physical health. Providing flexible, cafeteria style plans also gives employees with psychiatric disabilities a variety of options to meet their health coverage needs.

Sick leave policies can also be modified to allow the use of sick leave for mental health reasons—rather than limiting sick leave to physical health conditions; for example, sick leave or unpaid leave can be advanced for psychiatric hospitalization. Occasionally, companies have allowed other employees to contribute sick time to another employee.

Another strategy that employers can use to respond to the needs of employees with disabilities is to establish a conflict resolution panel (Zuckerman, et al., 1993). This panel might function as a resource in identifying reasonable accommodations as well as for appealing company decisions concerning them. This strategy demonstrates a commitment to involving others in decisions regarding accommodations and provides the employee with psychi-



atric disability with recourse should an accommodation initially be denied.

Clearly, there are a variety of things that employers can do to create an open, accepting environment that is conducive to disclosure. Employers benefit by creating a company situation which promotes diversity, recruits and retains talented employees with disabilities, and provides employees with the feeling that the company is one which is concerned about its employees and their welfare. Mental health consumers and service providers are in a unique position to assist employers in making the changes needed to create an employer open to employing people with psychiatric disabilities.

***The first strategy is to survey employers regarding their needs for information about mental illness. . . .***

## **Consumer and Provider Interventions**

Mental health consumers and service providers can do much to help employers promote acceptance of people with psychiatric disabilities in the workplace. The first strategy is to survey employers regarding their needs for information about mental illness, how to recruit qualified applicants with disabilities, what rehabilitation services are available to support employees and employers, effective supervisory strategies, ADA and its impact on people with psychiatric disabilities, reasonable accommodations, and other topics. One consumer organization has developed a Mental Health Resource Center based at McLean Hospital in Belmont, Massachusetts. This center has a corporate re-

lations division which surveyed employers in the Boston area about their interest in various topics and is planning educational programs for employers.

Rehabilitation service providers and consumer-run employment programs can also refer *qualified* applicants to employers. Employers are looking for potential employees who are able to do the job with or without reasonable accommodations. While some employers are also interested in hiring people with disabilities for altruistic reasons, the bottom line is that the work needs to be done. It is good business to hire people with disabilities only if they are qualified to do the job. The more qualified the applicants referred by consumers and providers are, the more real is the assistance provided to employers, and the greater will be the credibility the organization has with the employer.


Service providers and consumer-run employment programs can also offer supported employment services not only to referred applicants, but also to other employees with psychiatric disabilities who may need such services. For people with psychiatric disabilities, this might involve much more offsite, discreet support than onsite technical training in job skills. It is also important for employers to be sensitive to confidentiality issues in referring the employee with the disability, especially regarding the employee's coworkers.

A related service already mentioned is employee evaluation. Service providers and/or consumer employment programs could inform employers about assessment and consultation services available for their employees with psychiatric disabilities experiencing job performance problems.

Finally, general worksite education and training programs can be implemented based on survey results. In particular, employers may be looking for experts in ADA and mental illness, effective supervisory strategies identifying reasonable accommodations, interviewing and responding to disclosure of psychiatric disability, changing the workplace culture, and a variety of other topics. This education can be of-

fered in several different ways—as in-service training at specific work-sites, at employer breakfasts, at other special events, or in publications. For example, the Manic-Depressive and Depressive Association in the Boston area and the Eli Lilly and Company sponsored an evening of panel discussions on depression in the workplace; special displays and information on networking were also provided for area employers. The Boston Federal Executive Board (representing each referral agency in the Boston area) designed their October Disability Awareness Month event in 1993 to focus on psychiatric disabilities. This event included workshops on psychiatric disability in the workplace and reasonable accommodations, as well as a luncheon and an awards ceremony for employees and supervisors of the year.

## **Conclusion**

The strategies mentioned in this article are only a few of a range of interventions that can help employers create an open, accepting work environment. Several of the references on psychiatric disabilities in the workplace cited in this article are excellent resources for employers. Many employers are already beginning to institute culture change in their workplaces and including people with psychiatric disabilities in the work force. Rehabilitation and supported employment service providers and mental health consumers are in a unique position to facilitate the needed changes to increase the employment status and acceptance of people with psychiatric disabilities. 

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## Next Steps in Social Security Disability Process Redesign

Moving ahead with the initiative to redesign how Social Security disability claims are processed, Shirley Chater, Commissioner of Social Security, has released *Disability Process Redesign: Next Steps In Implementation*. This blueprint describes how the agency will develop, test, and implement dramatic improvements in the disability process. Copies of the document can be obtained by calling 1-410-966-8255; writing to SSA, Disability Process Redesign Team, Box 17052, Baltimore, MD 21235; or via Internet (access at World Wide Web (WWW) Server ([www.ssa.gov](http://www.ssa.gov)) or [gopher.ssa.gov](mailto:gopher.ssa.gov) or <ftp.ssa.gov>).

In releasing the plan, Commissioner Chater said, "This strategy document describes the 'who, what, and where of implementation and provides a timetable and staging plan for the various features of the redesigned process. . . . In response to the need for urgency, we have developed a set of short-term initiatives to reduce pending workloads and processing times. These short-term initiatives will aggressively address our current disability workloads."

Calling *Next Steps In Implementation* an action document, Chuck Jones, recently named Director of the Social Security Disability Process Redesign Team, said, "It describes our best thinking on when specific process changes will actually occur . . . and . . . the underlying structure we have put in place to facilitate disability process change at SSA and the DDS's [Disability Determination Services in each of the states]."

"*Next Steps* . . . is not a final plan. This project is too large and too complex to be fully charted or outlined at such an early stage—plus, it is to all of our advantage to continually look for opportunities to accelerate change. Due to the dynamic nature of this document, I invite your recommendations to proceed."

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# Mental Health Consumers as Professionals: Disclosure in the Workplace

Melissa Roberts, M.A.  
Jacqueline Rotteveel, B.A.  
Ed Manos

**D**isclosure in the workplace is a topic that mental health consumers have struggled with for years—some of us in our personal experience; each of us in our professional roles as we support people with mental illness in becoming employed. Over and over again we have come face to face with the dilemma of the choice, the agonizing decision and the wonderful and/or devastating results. We have examined our experiences, we have spoken to more than 100 consumers about their experiences, fears, and beliefs about disclosure. Over and over again we have been struck by the power of stigma in influencing the de-

cision and the power of disclosure in addressing stigma.

Any discussion about disclosure on the part of mental health professionals has to begin by addressing the often asked question of whether or not people with mental illness should work as mental health professionals, an issue which has generated a great deal of discussion over the past few years. Opinions on this topic have been quite varied, including “Absolutely not,” “Yes, but not where the person is receiving or has received services,” “Only if they don’t have access to confidential files,” and on and on. In truth, people with mental illness have been working as mental health professionals for a long time. They have simply chosen not to disclose.

Now, as the idea of people with mental illness as mental health profession-

als is gaining acceptance, another issue emerges: does the presence of a mental illness in and of itself make someone a good practitioner? Consider the following counselor’s experience:

“As a mental health professional and a consumer of mental health services both past and present, I have known for years, dating back to several hospitalizations in the early seventies, that I possess some inherent skills that allowed me to reach my fellow patients. Many of the professional caregivers at that time, despite their advanced degrees and proficiency, could not obtain the same level of communication with their patients that I, an untrained and obviously very disturbed young man, was able to accomplish with ease. I was referred to as the ‘Pied Piper!’

“Once upon the road to recovery, while taking jobs in the only field I was trained to do (security), I remembered the things that my professional caregivers had said to me; things such as, ‘It is too bad you became ill, you would have made a heck of a social worker or therapist!’ I remember wondering why I couldn’t still set my goals in that direction. I hadn’t realized that I was experiencing my first brush with stigma within the system. After literally infiltrating the system and becoming an entry level psychosocial worker in a small community mental health center, I moved to my current position where I meet and work with many fellow consumer/practitioners of varied degrees and specialties. Many of these colleagues have reported very similar experiences to my own in interacting with fellow consumers over the years. This ability to reach others had drawn them, also, to a field that stigmatizes as badly or worse than society as a whole.”

*The decision to disclose the presence of a mental illness in the workplace is one of the most difficult struggles facing any mental health professional who is also a consumer. The benefits of such disclosure are many, including the increased availability of support or accommodation as well as the additional knowledge the individual may bring to the professional role. The risks of such disclosure are also great as stigma exists in the mental health profession to a degree at least equal to society at large. This article addresses some issues that may emerge for people who choose to disclose. It focuses on how and why one might disclose, the potential results of disclosure, and strategies to deal with negative reactions. The article also discusses ways in which the employer, coworkers and other significant people in the worker’s life can support the individual and minimize the risk of disclosure.*



Today, because of changing attitudes as reflected in the Americans with Disabilities Act and because other consumers across the country have disclosed their backgrounds, the field is slowly opening its doors to both those new professionals who disclose at the time of hire and those professionals who, in a clandestine way, had entered the field and may now choose to disclose. Some educational programs such as the psychosocial rehabilitation and treatment degree program of Middlesex County College and the University of Medicine and Dentistry of New Jersey have actively recruited consumers, with career goals of becoming professionals, with the intention of providing needed accommodations and supports.

The choice to work in the mental health field, like any other career choice, needs to be based on interests, preferences, and skills. When individuals make this choice for other reasons (i.e., seeking power or control; thinking they can get even with the system by working from within) and in the absence of adequate skills, the professional is less than effective, regardless of the presence or absence of a mental illness.

It is our belief that it is the presence of helping skills that makes an effective professional. An individual with these helping skills, who also has personal experience as a consumer, may bring added insight and resources to their professional role. Simply having experience as a consumer, however, does not guarantee that one will be an effective professional.

The decision to disclose the presence of a mental illness to one's employer, coworkers and/or clients is fraught with consequences. There are many benefits to disclosing and just as many problems. Disclosing enables you to ask for accommodations and supports which may be difficult to explain otherwise. It gives you the opportunity to connect with clients not just as a professional but also on the basis of shared experience and to be a resource to clients and colleagues for information learned only through experience, such as medication side effects which are not listed in the resource books or ways

to cut through the red tape and get the services you need. You may become a role model for clients as well as a challenge to some long-held beliefs. Unfortunately, disclosure may also make you an easy target for negative feelings people may have about consumers. Through our own experiences and after talking to more than 100 consumers about the issues associated with disclosure, we are convinced that in most employment settings it is wise to explore the "who, why, when, how, and how much" of disclosure before deciding. We are also convinced that disclosure in the workplace should absolutely never be mandatory.

***Before deciding to disclose in the workplace it may be necessary to make an assessment of the readiness of coworkers, administrators, consumers, and other staff. . . .***

Before deciding to disclose in the workplace it may be necessary to make an assessment of the readiness of coworkers, administrators, consumers, and other staff to handle this disclosure in a positive way. You may want to decide who you would tell first. Confiding in a trusted colleague establishes an ally who may be helpful later in dealing with less positive responses. Knowing why you want to disclose and what reactions you are expecting may help you plan what to do if reactions are different from those expected. Deciding when, how, and how much to disclose depends in part on the culture of the workplace. You may want to examine the ways in which staff support each other: informally before program hours begin, formally in a staff support group, meeting after program hours for coffee or a drink. How much tolerance is there in this work setting for discussing any personal information?

Although each person's experience with disclosure is unique, what seems to be true most of the time is that it is better to start small. Once something has been said it cannot be taken back.

Those whose job it is to support people in becoming and staying employed need to be willing to work with people to answer those questions and willing to accept the individual's decision, as represented in the following:

"John and I were returning from visiting one of our clients in the hospital when, for the first time in the year I had worked at the community mental health agency, I began to get down and personal with him about my own mental illness. For 8 hours every day, I worked with people who had many of the same symptoms and problems I had; who were taking medications I had taken; and had been treated by professionals and hospitals that I had also used. Afraid that my having this same mental illness would somehow 'disqualify' me from being able to work at the agency, I kept silent. I was afraid if they knew they would fire me. But the stress of keeping the secret had become unbearable. John's reaction was crucial but, I felt, predictable, based on the friendship we had developed. His support and encouragement enabled me to go on and disclose to my supervisor. But I also wanted to share the hope of recovery with the clients I worked with, and let them know there was a way back from what felt too often like a pit of darkness; I wanted to share the struggle of living with this illness, both the good and the bad, with others

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who had it, and with my colleagues. My supervisor and I discussed how and when to disclose to the rest of the agency. We explored what to disclose, the possible reactions, ways to respond to these, and where this disclosure should take place. We weren't sure what people's reactions would be but I knew I had her support. We agreed that the first step was to disclose to staff in the weekly staff support group. Soon after, I began disclosing openly to clients as well.

"The initial reactions were positive. I was respected for my work, so my professionalism wasn't called into question. At times, as my colleagues experienced their own struggle with what it meant to have someone with a mental illness actually work in their agency, alongside them and their clients, less positive reactions occurred: hurtful statements, thoughtless jokes. At such times it was helpful to talk to my supervisor to gain perspective on the event and to sort through my feelings about it. For the most part I became a source of first-hand information for colleagues, a role model, and, at times, a frightening anomaly for clients, and I took on a new role: consumer advocate."

The availability of a supporter—counselor, supervisor, coworker, friend, family member, or anyone else the individual chooses—often makes the critical difference in the individual's ability to deal with all the reactions to disclosure that he/she is likely to get. This is particularly true when the reaction is not what was expected or is not positive. Although often the results of disclosure are constructive—such as coworkers and employers expressing interest in the experience of mental illness, recognizing a challenge to notions that consumers are incapable of working or working as professionals, and exhibiting a general decrease in negative feelings and beliefs concerning people with mental illness—this is not always the case. For some people, knowing that a colleague is a consumer does not affect their feelings about consumers; rather it affects their feelings about their colleague. To illustrate, consider the following experience:

***Potentially, the willingness of the mental health professional who is a consumer to disclose is beneficial to everyone in the worksite.***

"Disclosing to my coworkers at the agency left me open as a target for any of that leftover, hidden stigma against mental illness that may exist. And because I was not one of their 'clients' but a competent colleague, it appeared that I was strong enough to stand it. I was fair game. One of the most painful events that I ever experienced involved a simple gum eraser.

"One morning, before the day program activities began, I came in to work on my paperwork. I opened my desk drawer to get my pen, when I noticed my gum eraser out of place, with something written on it. I took the eraser out and laid it on my desk—no easy task as my hands began to shake. Written with pen on that eraser was the word 'crazy.'

"One of my colleagues, in this staff-only office, had gone into my desk, taken out my eraser and written 'crazy' on it. I was dumbfounded. I couldn't imagine anyone doing such a thing. The people in this office were my colleagues and friends. Disclosing hadn't seemed to change any of that. Until now. I brought the eraser to my supervisor, who understood its impact. She was shocked and supportive. We talked about the incident, the possible meanings, potential responses. I left to go home, too shaken to work. I cried my way home, questioning my judgement in ever disclosing. Painfully, I realized I couldn't unring that bell. I realized that no matter where I went, stigma and oppression, ignorance and fear, were going to be an ongoing struggle. Stigma was the shadow that would always be there.

You can't turn on the light without creating shadows behind you. Fear and ignorance run so deep, and are so powerful. But I was going to have to find some way to put it in perspective, to continue to educate and advocate at every opportunity. I had fallen into this struggle with both feet running, whether I liked it or not. Unfortunately, and perhaps in the saddest way, I realized I'd have to be educating even my own colleagues. But the pain ran deep. Just like it does every time it happens, as it has over and over again through the years. I carry that eraser with me, to remind me that stigma can be as simple as five letters, written with pen, on an eraser, hidden in a desk drawer."

Experiences like this illustrate the importance of having a friend, colleague, or supporter who can understand the impact of such an event and help the individual process the pain and move beyond it: but this is not enough. The culture that exists in a workplace is made up of both the formal rules, policies, norms, and rituals and the informal, unwritten ones. Agencies that provide services to people with mental illness need to examine their mission and values and courageously assess whether or not the culture sets a tone of respect, support, and hope for everyone.

Potentially, the willingness of the mental health professional who is a consumer to disclose is beneficial to everyone in the worksite. The agency has the opportunity to "walk the walk," to demonstrate its beliefs in the capabilities of people with mental illness. For agencies that provide vocational services to people with disabilities, this is particularly powerful. Staff within these agencies gain an invaluable resource: someone who has experienced the system from the other side and may know what some medications feel like, what to expect at the Social Security office, ways to manage symptoms, etc. Staff also gain the opportunity to examine their own beliefs and attitudes and re-evaluate any which may have created barriers to consumers' goals. Nowhere is the benefit of disclosure more obvious than in the impact it can



have on consumers receiving services at that agency, as shown in the following:

"Being open about my own illness seemed to make a great impact on some of our clients, particularly since I worked helping people find jobs. Time and time again, clients would come to me asking about my illness, telling me that it looked like I coped so well and that they didn't cope well and that maybe I could work, but they'd never be able to. I'd spend time talking with them about the support and treatment behind the scenes that made it possible for me to do the things I want to do. Without going into details, we talked about using medications and therapy and support systems of all kinds to get through the day; and that my symptoms were serious and severe some days, just like theirs were, and that I could still work, just like they could. And sometimes it was like watching a light go on again behind their eyes. At first, they stared at their shoes, muttering about that dream they used to have of being a school crossing guard. And then that pause, waiting to hear what I'd say. I'd ask them what kind of help they'd need to achieve that dream, and specifically, how could I help support them. They'd look up, wondering whether I was serious. I'd look back, and remind them that this agency had hired me to be their casemanager, something I'd never thought I'd be when I was sitting in the same chair they were sitting in, across from my psychiatrist. And in a world where their casemanager struggles with the same painful illness and symptoms as they did, who knew what the limits were to what could happen? We'd share a laugh over that. Sometimes I'd see a little spark come back into people's lives as I reminded them over and over that their dreams were no more ridiculous than mine. And with the right supports, I'd managed to make mine happen. So could they. It's one thing for a doctor to tell you what you can and can't do, based on their experiences of working with other patients. It's something else altogether for someone with the same kind of illness you have, a peer, to show you that dreams don't

have to die, that you can still go after what you want and sometimes get it, just like other people. It was a time of helping people reclaim their dreams, helping them see, often with some humor, that if their casemanager struggled with this illness like they did, then why couldn't they be a school crossing guard? or a teacher? or drive a car? or have their own apartment, too? Me? I just sat there, shrugged my shoulders, and said 'Why not?'"

Sometimes the impact of disclosure is the assignment of a new label: hero. The individual who pursues their life goals and manages their mental illness is seen as unusual, as a kind of "super consumer." This is particularly true if the individual is articulate and outspoken about the needs of people with mental illness, for example:

***"Sometimes I'd see a little spark come back into people's lives as I reminded them over and over that their dreams were no more ridiculous than mine."***


"A long time ago, someone gave me a piece of advice I've never forgotten: 'Never believe the best or the worst people say about you.' When clients' symptoms flare, and they need a target for their rage, I've been able to protect myself from personalizing that anger by remembering that advice.

"Unfortunately, it's a bit harder with all the best that people say. Whenever I'm asked to do a speech or presentation, I make it a point to remind the audience that what I say and do is not special; that people with mental illness

do what I do all the time—work hard to achieve their goals and be the best they can be—and that there are millions of people with this illness who cope as well, perhaps better than I. Invariably, there are those who come to me with tears in their eyes and outrageous praise on their lips. They tell me how wonderful, brave, and courageous I am. It's not that I don't believe I am. It's not a self-esteem issue. It's that being that kind of a 'hero' makes me uncomfortable. The higher people put me up on a pedestal, the further down I'm convinced I'll be falling one day. And the farther away they are from understanding the message. The message is about people with mental illness being people, just like we all are. People with wants and needs, hopes and dreams, fears and desires. People who can write and paint, work, and raise children. People who have skills and abilities, as well as serious struggles and obstacles to overcome. People who need help and people who can give help.

"As long as people see me as a hero, they're missing the point. I'm not special. I'm just like everyone else. So whether they hide erasers with 'crazy' written on it in my desk drawer or hoist me on their shoulders and call me a 'hero,' it's nothing more than the shadows of stigma, and sounds of the struggle that still needs to be fought."

When the reaction to disclosure is "You're so wonderful to have accomplished what you have," sometimes the hidden message is "because most consumers can't." This may be an excuse for continuing to deny people opportunities to pursue goals and dreams.

Disclosure is a risk, and taking that risk is an individual choice. There is no one right way, time, or reason to disclose. The risk, though, can be minimized by the availability of a supportive person, an understanding of the reason for disclosure, and a plan for dealing with unexpected reactions. Professionals and agencies can minimize the risk by creating a work culture in which all people are respected for their individuality, valued for their contribution, and supported to do the best job they can. 



# The Social Center for Psychiatric Rehabilitation: Adapting to Change

***Treatment and rehabilitation of people with serious mental illness have made enormous strides in the past 20 years. Described in this article are the philosophy and services of an established psychosocial rehabilitation program, along with suggested adaptations for changing populations and the use of philosophy and outcomes to guide program change.***

Vera Mellen, M.A.  
Stephanie Cobb, M.A.

Psychosocial rehabilitation, which encompasses both a philosophy and a set of interventions, is a rehabilitation choice that offers positive outcomes in addressing issues of serious mental illness. There are over 2,000 programs offering psychosocial rehabilitation in the United States and, while they may vary, they all, in general, offer or coordinate a variety of integrated services (i.e., vocational, social, recreational, residential) in a holistic and comprehensive manner to individuals with serious mental illness. They also share basic core values, including:

- helping individuals to develop normalizing roles and relationships,
- addressing practical and realistic aspects of adjustment and needs,
- facilitating learning through experiential activities, and
- minimizing differences in roles, authority, and status between staff and members (Rutman, 1994.)

Integrated services, implemented in an environment faithful to these values, help individuals with serious mental illness to move ahead in their recovery.

The Social Center for Psychiatric Rehabilitation (or Social Rehab Center), one of the nation's oldest psychosocial rehabilitation programs, annually provides a wide range of social, residential, vocational, and case management services to over 600 adults in the Northern Virginia communities of Merrifield, Englewood, and Reston. Founded in 1963 as a free-standing, private, nonprofit corporation, its mission is to provide comprehensive, well-integrated services to adults with serious mental illness so they may attain the highest possible quality of life by acquiring the skills and resources needed to live, learn, and work in the community of their choice. The agency is governed by an active volunteer board of directors that is representative of this suburban community of Washington, D.C.

Since its inception, the agency has been dedicated to providing whatever supports and services are needed by people with severe mental illness to live successfully in the community. It is this commitment to a target population, rather than to any one rehabilitation approach, that is the center's strength. Services which help members meet their goals are continually developed and evaluated for their utility and effectiveness. Programs and services

are driven by the needs identified by members, not by staff interests and/or skills, and are interwoven with a sense of hope. These values are highly congruent with the basic values of psychosocial rehabilitation and the emerging recovery vision.

Recovery refers to the process of restoring something lost. Mental health consumers can utilize the assistance offered in psychosocial programming to regain normalizing roles in their lives, such as that of a husband or wife, community resident, or worker. Anthony (1993) makes the distinction that *individuals* recover; service providers *assist* to facilitate the process; ownership of the process belongs to the consumer. Hence, empowerment is a critical component of the recovery process. Recovery means more than the removal of symptoms. Recovery refers to the change of attitudes, values, feelings, goals, skills, and/or roles such that an individual lives a satisfying and meaningful life, even with limitations caused by the illness itself.

## Characteristics of Serious Mental Illness

Individuals with serious mental illness comprise a heterogeneous group with varying diagnostic labels. The most common diagnoses are schizophrenic disorders, major affective disorders, such as depression or bipolar (manic-depression), and/or serious anxiety or personality disorders. Individuals can be dually diagnosed with more than one disorder, such as having bipolar disorder and a personality disorder, or schizophrenia and a learning disability. There may be concomitant physical health conditions, such as epilepsy, diabetes, or deafness.





*Members of the Program Support Unit (Melba Pastrana-Hart, Michael Hart, Margaret Hood, and Pam Mullarkey ) working on items to be used in fundraising.*

Serious mental illness causes severe disturbances in thinking, feeling, and relating. When discussing the effects of mental illness, it can be useful to group them under three categories. First, individuals must cope with acute or positive symptoms. In schizophrenia, for example, this may involve experiencing hallucinations or delusions. For individuals with bipolar disorder, these acute symptoms may include extreme "high" moods (mania) or extreme "lows" (depression).

Individuals with severe personality disorders may experience periods of intense, fearful and chaotic feelings that lead to maladaptive and/or self-destructive thoughts. While medication management has been effective in reducing or eliminating some of these acute symptoms, individuals also experience residual effects of their illness, called negative symptoms. These may include such things as anhedonia (diminished ability to experience pleasure), apathy (lack of feeling), social with-

drawal, poverty of thought (slow and confused thinking), blunting of emotion (emotional insensitivity), slowness of movement, lack of drive, and vulnerability to stress (Hughes, 1994).

Finally, individuals may experience secondary symptoms that are attributed to both the individual's and the community's response to mental illness. These may include a sense of hopelessness and helplessness, low self-esteem, fear of taking risks, and the trauma of dealing with society's stigma and fear regarding mental illness (Hughes, 1994).

## Program Components

The center's rehabilitation program helps members compensate for or eliminate functional deficits, interpersonal skills deficits, and environmental barriers created by the disability. Through skill and resource development in a supportive atmosphere, individuals can restore their ability to live independently and effectively manage their lives. The program components described below are designed to restore a sense of confidence and hope, increase self-esteem, build on strengths, and emphasize wellness vs. illness.

## Clubhouse Units

Using an approach known as the clubhouse model, the center provides a supportive environment in which people with psychiatric disabilities participate as members, rather than as patients. Members with and without vocational goals participate in the work units, which serve as the foundation of the program and therefore contribute to the daily operation of the center. Based on their interests and skills, members of the center choose from among the business/clerical, consumer advocacy, support and education (C.A.S.E.), food, mainte-

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*Ms. Mellen is Executive Director of The Social Center for Psychiatric Rehabilitation and Ms. Cobb is Supervisor of Vocational Services at the Merrifield location.*





Kim Wilson and Heide Atwood prepare lunch in the Food Unit.

nance, and thrift shop units for their daily participation. In these units, members learn important work, socialization, and problem solving skills; make friends; and build self-confidence. For example, the business unit performs clerical tasks, teaches computer skills, and publishes the members' newsletter. The clubhouse units are also supplemented by a variety of educational and support groups. Because the center strives to be a "no-reject" agency, members come into the program with a variety of skills and goals; consequently, no one rehabilitation plan will meet all needs. It is, rather, the availability of a comprehensive array of easily accessed services that results in successful vocational outcomes for 40 percent of members served.

## Vocational Program

Utilizing material developed by Anthony and his associates at the Boston University Center for Psychiatric Rehabilitation, members work collaboratively with staff to develop individual goals and plans, many of which focus on choosing, getting, and keeping jobs.

Prior to 1992, the center operated two thriving business ventures: *Merri-field Mailings* provided bulk mailing services to area businesses and *SRC Tees* produced a line of silk screened tee shirts by special order. Both businesses met the Department of Labor definition of sheltered workshops, offering members an opportunity to gain work experience and to earn less than minimum wages within the center's supportive environment. However, in

1992, a series of satisfaction surveys indicated that these workshop experiences had not been helpful to members in moving on to community-based employment. Over the next several months, the two businesses were closed and the agency focused on improving its community-based job development and employment activities. Members now focus on preparing for and entering into two different types of employment, namely:

- *Transitional Employment*, in which members who are not sure about either their vocational capacities or their employment goals have the opportunity to be placed in one or several entry level, short-term (6-month) placements in the community at competitive (rather than sheltered) wages; and

- *Supported Employment*, in which members who have more definite career goals are assisted in gaining and maintaining permanent employment and are supported by agency staff on the job to assure both short-term and long-term success.

Members are active partners in the process of locating these job opportunities for themselves through the operation of the center's Job Resource Center, which is open to all members in the program. The Job Resource Center at each location offers members staff support, peer support, and practical services in their efforts to find work. In addition to being a physical location within the larger center, the Job Resource Center is also a set of supports for the member seeking work.

The Social Rehab Center's vocational program has four major phases or components—job preparation, job development, initial job stabilization, and long-term followup—and is an approved vendor of vocational services through the Virginia Department of Rehabilitative Services. All components have been developed in response to member needs and available technology. Members come into the vocational program from either the clubhouse or from direct referrals from the Department of Rehabilitative Services. It is important to note that, while the following description of interventions is



presented sequentially, members are not required to utilize all components, nor to use them in sequence.

## Job Preparation

Job preparation begins as soon as the member is accepted into the program and continues until the member begins seeking a job. The major objectives of this phase are to ensure that the members are job ready and to help them choose the type of employment they wish to pursue. Services provided in this phase include:

- *Assessment.* For individuals referred directly into the vocational program, assessment includes obtaining referral and background information, such as clinical history, work history, and educational background. Personal interviews are utilized to gather behavioral observations of interpersonal skills, grooming and dress, and the member's assessment of services needed and desired. Situational assessments, deemed a quality predictor of vocational ability (Cook, Jonikas, & Solomon, 1992), are utilized through participation in the Job Resource Center.

Members also develop written functional assessments as part of the overall service plan. Each member works with a vocational staff person to prioritize defined skill and/or resource deficits in terms of urgency, motivation, capability, and availability of support.

The Job Resource Center at each location makes available an array of vocational services that can be easily accessed by any member wishing to pursue a job goal. Services listed below are designed to meet members' needs at any stage of their vocational plan, whether it be choosing, getting, or keeping a job.

- *Job Matching.* Individual and group activities in career exploration and in job choosing (career counseling) are provided within the Job Resource Center by the vocational counselor. Members learn about the world of work through jobsite visits in the community and from speakers invited to the center to describe various employment settings. Additionally, the vocational

counselor assists members in gathering previous work history information, administers vocational interest inventories, facilitates exploring job values and job skills, and then helps members match individual skills, abilities, and values to specific jobs and careers.

***Job preparation begins as soon as the member is accepted into the program and continues until the member begins seeking a job.***

- *Job Keeping.* Through the functional and situational assessment process stated above, members identify their skill strengths and needs and begin to understand how their deficits interfere with their ability to keep a job. They

then learn how to remediate these skill deficits through the development and implementation of a rehabilitation plan. Skills identified in a person's Individual Service Plan (ISP) are worked on initially within the Job Resource Center and are reinforced, as needed, during the placement and followup period.

## Job Development

Once a member is job ready and has targeted a field, the job development phase begins. The objective of this phase is to help the member secure employment in his or her chosen field. Services provided in the job development phase include:

- *Job Location.* Job location assistance is provided through a combination of two vehicles, the *job developer* and the *job club*. The job club uses a modification of Azrin and Besalel's (1980) work and focuses on getting a job in the community through active participation in structured activities. These activities include locating job leads, practicing interviewing, evaluating grooming, writing résumés, and making daily contacts with prospective employers with the assist-



*Shelby Holley, Job Developer, talking with Max Linovitz, a member of the center, about future vocational plans.*



ance and support of vocational staff and fellow job seekers. To help facilitate a successful job search, a wide variety of resources is readily provided, such as the use of telephones, computers, newspapers, and stationery supplies. Eighty percent of members use the full support of the job developer. Twenty percent request consultation to support their individual actions. After initial openings are identified, job developers engage in extensive outreach to the business community to secure jobs for members. If requested, job developers will go on interviews with members and then provide feedback and additional training and practice as indicated.

- *Employer Education.* The job developer assists employers in increasing their understanding of mental illness/etiology, symptomatology, and rehabilitation methodologies. Attention is given to separating the symptoms of the illness from the strengths of

the individual. Member confidentiality is protected during this process. Additionally, employers are provided with information and feedback on their rights and responsibilities under the Americans with Disabilities Act.

- *Pay and Benefits Negotiation.* The job developer works with the member to negotiate wages. Members always earn wages and benefits equal to that being paid to nondisabled individuals in the same position. Members who are currently working and have been placed by the center earn between \$4.25 and \$11.00 per hour. Job coaches continue to review and advocate together with the member for increased pay and benefits commensurate with his/her performance and the employer's policies.

- *Job Accommodation.* Part of the job choosing process involves helping members to decide whether or not to disclose their disability. If they choose to do so, members learn to identify

needed accommodations based on specific functional limitations. They may need to practice with the vocational counselor on how to present their needs to employers. In the job getting phase, the job developer negotiates any needed accommodation in the job before placement. After placement, the job coach may negotiate other accommodations. Some examples may include arranging part-time or reduced hours during periods of increased psychiatric symptomatology, allowing for short breaks during the workday, or restructuring part of the job to allow for maximum productivity.

## Initial Stabilization

The objective of this phase is to help the member meet the demands of the new job. Once a job has been found, the job coach works closely with the client and the employer to help the client succeed in the job. During this phase, intensive on- and off-the-job supports are provided as needed; these services include:

- *Orientation.* Job coaches assist members onsite in learning the routine of the work environment, role modeling interactions with coworkers and supervisors, and providing support during the initial period of employment. Assistance is provided in filling out paperwork, such as tax forms, etc.

- *Followup Visits.* Members in individual placements are visited weekly by vocational staff, as warranted, usually for the first 6 months. During visits, the member, his/her supervisor, and the staff person meet to discuss job related issues. The frequency of followup visits decreases in accordance with member needs. Follow-along services continue as needed on an individualized basis.

- *Medication/Symptom Management.* Members often need assistance in making regular therapy and medication appointments and in notifying therapists and psychiatrists when there is a change in psychiatric symptomatology. Vocational staff assist with this process.

- *Natural Supports.* Job developers and job coaches identify and facilitate



Charlie Erkkila completes a wordprocessing job in the Computer Room of the Business Unit.



natural supports in the workplace. These supports include pairing members with other experienced workers within the employment site to orient the new worker—adopting a consultant's role with the worker's supervisor vs. taking on supervisory tasks directly—and to interpret the workplace culture. Job coaches assist new workers to identify their commonalities with nondisabled coworkers so they may further their social integration. Members of the Social Rehab Center Board and other community contacts sometimes serve as mentors.

- *Financial Planning.* Members receive intensive education regarding how returning to work may impact either their public supports or their disability income. Members are also assisted in reporting wages to the Social Security Administration and in advocating for help with Medicare and Medicaid. Additionally, members are given support and technical assistance during the benefit review process. Technical assistance with work incentives, such as the Plan for Achieving Self Support (PASS) and Impairment-Related Work Expenses (IRWE), is also provided.

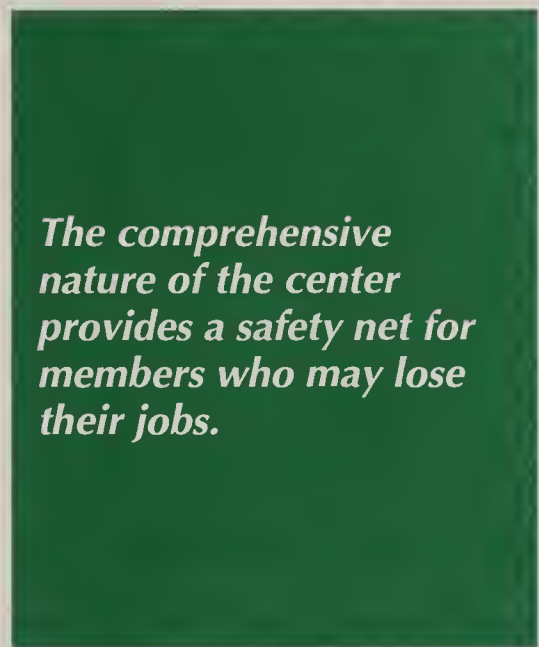
- *Transportation.* Assistance with transportation planning, with hands-on training if necessary, is provided by vocational staff. Members are assisted in learning a new route by bus or Metro, or in learning the entire public transportation system.

- *Family Involvement.* The Social Rehab Center has worked with families since 1974 and regularly offers psychoeducational support groups. Topics discussed include medication, utilization of the mental health service delivery system, social isolation, and other familial concerns.

Family members are supported and encouraged to form a partnership with staff in providing services to members. This may take the form of families participating in team meetings, in update sessions, or simply talking periodically by phone about their family member's involvement and participation. The level of family involvement varies from individual to individual and, as adults,

members have choices regarding the level of family involvement.

- *Emergencies.* Staff from the Social Rehab Center intervene on the jobsite during periods of crisis. Interventions may include responding onsite to crises, assisting members in obtaining emergency services, and negotiating with employers for time off during periods of stabilization.



***The comprehensive nature of the center provides a safety net for members who may lose their jobs.***

### **Long-Term Followup**

Once members are stabilized on a job they move into the long-term followup phase. The objectives here are to ensure that members remain employed and that they have the opportunity for career growth. Services offered include regular monitoring of the members' progress and the provision of support services described in the stabilization phase, as needed. The agency will have at least two face-to-face contacts with the member and one contact with the employer every month. Other services specific to the long-term followup phase are:

- *Follow-Along Groups.* The job follow-along group is a support unit for members who are working and is designed to increase job retention rates. The group has two main functions: to assist members in resolving work related issues and to provide peer support. Types of issues addressed may include communication skills, conflict

resolution, accepting constructive criticism, dealing with anger appropriately, etc. Peer support is vital to help offset the isolation many clients feel and in offsetting views that their problems may be unique. Staff facilitate these groups and, together with peer group members, offer support, encouragement, and opportunities to problem solve and role play difficult situations. Groups are held at different times to accommodate varying work schedules.

- *Assistance with Re-Employment or Job Changes.* The comprehensive nature of the center provides a safety net for members who may lose their jobs. Support is available as needed and individuals may return and make use of the Job Resource Center.

Additionally, members are encouraged to think about career ladders. Job choosing skills are taught with the understanding that members will likely use them in making job changes. Members are assisted in making job changes for better pay, higher skill levels, and opportunities for advancement.

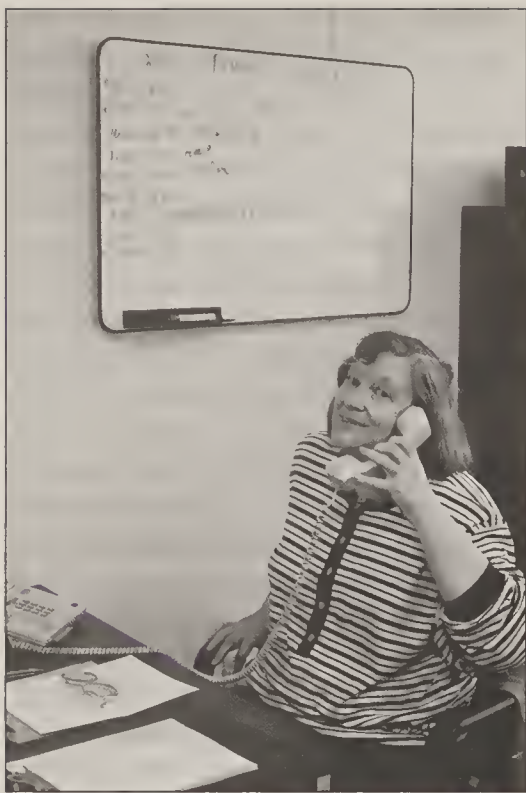
### **Adapting to Changing Populations**

Historically, the center has primarily served individuals with schizophrenia. Over the years, the characteristics of this population have changed; client demographics and member satisfaction surveys have documented these changes. The following section will address two emerging populations and the specialized interventions developed at the center to facilitate their recovery.

### **Mental Illness and Chemical Dependency**

An emerging issue in service delivery for people with serious mental illness, and certainly a factor in the development of vocational services, is what is termed the "young adult chronically mentally ill individual" (Pepper, Kirshner & Ryglewicz, 1981). Pepper et al. (1981) found that approximately half of the people receiving mental health services were between the ages of 18 and 30. Substance abuse was a major





*Orbie Duffy, a member of the Business Unit at the center, answers phones.*

issue with many; the incidence has been reported at 37 percent (Pepper et al., 1981). Many of these individuals turn to substance abuse because it allows them to be a peer member, alleviate stress, and behave more socially and it helps to medicate their symptoms (Ridgely, Goldman & Talbott, 1986.) A high risk of suicide (42 percent) is also reported among this group. Certainly, there are numerous issues to be considered in planning vocational programs.

At the center, we have developed an individualized, flexible substance abuse/vocational policy, with the goal of responsibly addressing the vocational and substance abuse issues and needs of all members who have a desire to work, but who also have a recent history or current indication of substance abuse.

Members interested in working will undergo a substance abuse evaluation/assessment or will have previous substance abuse assessments updated to determine the level of substance abuse counseling and support that the working member needs or requests.

Once a decision has been reached concerning the degree of support that

the member requires, a substance abuse/vocational agreement, tailored to meet the individual needs and goals of the member, is drawn up and signed. It should be developed by both staff and member and be both realistic and attainable. Members are encouraged to request a meeting to revise/amend their agreements if their needs and goals are not being met.

A waiting period may be required before a member actively seeks work. This time period is set aside to give the member an opportunity to focus on sobriety and to transition to the social, interpersonal, physical, and intrapersonal changes that accompany a new, sober lifestyle. Types of support offered include inhouse groups such as substance abuse education, relapse prevention, work and recovery, or Adult Children of Alcoholics groups. Some individuals may benefit from drug screens. With agency transportation, some members attend community Alcoholics Anonymous meetings during program hours. The member works to remain drug and alcohol free.

### **Borderline Personality Disorder**

Another increasing population being served at the center consists of those with Borderline Personality Disorder (BPD). BPD is characterized by unstable and intense interpersonal relationships, chronic feelings of emptiness and boredom, and frantic attempts to avoid real or perceived abandonment (Holland, Zippel, & Batscha, 1993).

Two aspects of the more traditional clubhouse environment can be counterproductive for working with persons with BPD. People with this disorder have difficulty in establishing boundaries with others; they experience difficulty identifying appropriate roles and expectations of others. Since psychosocial rehabilitation minimizes the role, status, and authority differential between members and staff, this can lead to role confusion for individuals with BPD. The second difficulty is that, traditionally, many of the activities of the clubhouse occur in a group milieu with an emphasis on hands-on

behavioral tasks. While this milieu can certainly be a good vehicle for assessment, it cannot be the sole environment for interventions. Persons with BPD need individual time and attention to process some of the cognitive and affective skill deficits they possess.

In a continuing effort to adapt our programs and services based on the needs of this group, several modifications have been made. Careful attention is given to address the affective and cognitive skill areas during the functional assessment process. Individuals with BPD are generally given additional individual time, perhaps daily time, to meet with staff and process feelings and reframe maladaptive ways of evaluating situations. This extra time also helps facilitate the member's trust and rapport with staff, which is crucial to their ability to tolerate the difficult feelings accompanying change. Three educational groups have been effective in working with members with BPD. One is "Understanding Your Illness." Many individuals with BPD have never been told of their diagnosis; helping them to understand how they may have increased vulnerability to interpersonal conflict is helpful. A sec-



*Pat Rogers works as a cashier in the Merrifield Thrift Shop.*



ond group, "Anger Management," involves helping members to identify the antecedents to their anger and helping to intervene before the feelings of anger escalate and contribute to a negative interaction. A third group, "Confidence," helps members to improve their interpersonal skills, especially their assertiveness and direct communication skills.

***In the future, as new populations emerge, our interventions will again be modified.***

These groups and the individual service planning process take place concurrently with other phases of job preparation for members with vocational goals. Successful strategies and techniques utilized during the job preparation process can then be continued with the job coach after job placement and through the follow-along groups.

In the future, as new populations emerge, our interventions will again be modified. One of the keys to our members' success is the ability of our staff to help them deal with psychiatric symptomatology and vocational issues at the same time.

## Program Evaluation


A management information system tracks client information, program services, and vocational outcomes. The system gathers information on the types of services used (e.g., attendance at the Job Resource Center, on-the-job and off-the-job supports) as well as the outcomes (e.g., number of days em-

ployed, wages earned, job changes) to assess the program's effectiveness. In FY '91, 24 percent of the members served in the clubhouse were employed, 29 percent were employed in FY '93, and 40 percent in FY '94. Employed members also complete quarterly *Member Satisfaction Surveys* (Bond & Miller, 1991) that document whether they are pleased with their work, pay, hours, supervisors, etc. Evaluation is a management tool for improving services and providing accountability to our funding sources.

## Summary

Treatment and rehabilitation for people with serious mental illness have made enormous strides in the past 20 years. Psychosocial rehabilitation programs have grown increasingly sophisticated in their ability to define best practices and to document client outcomes.

The International Association of Psychosocial Rehabilitation Services has recently provided a review of the literature citing the cost effectiveness of psychosocial rehabilitation. When contrasted with the high cost of repeated hospitalizations, high utilization of emergency rooms, unemployment, and homelessness, psychosocial rehabilitation offers substantially lower costs for better outcomes (Hughes, 1994).

National healthcare reform presents a special opportunity to educate the public on both the pragmatic cost-efficiency and the positive gain in human dignity found through these interventions. They help people to live more productive lives, and thereby to contribute more to society. 

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# Establishing Employment Services as a Priority for Persons with Long-Term Mental Illness

*Despite the widespread recognition of the advantages of employment—increased income, a structured day, social opportunities, and heightened self-esteem—far too little progress has been made over the past 20 years to improve the job prospects of those who have had a serious mental illness. In fact, the overwhelming majority of people with long-term mental illness do not work. There is considerable evidence that older research estimates of an 85 percent rate of unemployment remain valid. This article discusses a number of emerging issues which must be addressed before progress in this area can be realized.*

Richard Baron

**T**he staggering rate of unemployment among persons with long-term mental illness, many agree, cannot be an accurate reflection of their capacity to work. Clearly, something is wrong if the mental health and vocational rehabilitation (VR) systems are failing those they should serve. Far more needs to be done to insure that employment-related services become a priority in the overall rehabilitation of people who want to work, requiring changes at personal, programmatic, and policy levels.

At the personal level, each individual must have the opportunity to develop and act on his or her interest in em-

ployment. There is a prevailing assumption among many who work with persons with mental illness that employment is at best a secondary concern. Indeed, many consumers of mental health services remember all too well when they were first told they could never work and when, more recently, they were told they could not work yet.

At the programmatic level, many community mental health centers, psychosocial rehabilitation programs, and private psychiatric settings must begin to re-examine the ways in which they can make the goal of employment an important focus of their services.

At the policy level, a wide range of federal, state, and local agencies need to

explore ways in which funding priorities, regulatory strictures, and staffing patterns can promote, rather than inhibit, the hope of most consumers to find work.

Because those with serious mental illness are today a younger and less institutionalized group with more peer-appropriate life goals than ever before, it is irresponsible to continue to offer programming for them that does not have at its core a recognition of the role that employment must play in their lives.

It should be noted that the employment needs of this group have not gone entirely unnoticed, and indeed there have been a number of initiatives over the past several years to prioritize work. Psychosocial rehabilitation programs, for instance, have frequently developed transitional and supported employment programs that help people to work. The principles of these programs—reasonably rapid placement into a real job for real pay, intensive initial support on and off the job, and persistent ongoing support thereafter—have demonstrated considerable effectiveness in helping people to establish themselves as workers rather than as patients. In addition, both the Rehabilitation Services Administration (RSA) and the National Institute on Disability and Rehabilitation Research (NIDRR) have funded a variety of professional training and services research projects to help establish the importance of employment programming for this group. Also, at the Center for Mental Health Services (within the Department of Health and Human Services) there has recently been a major commitment of research and demonstration dollars to promote and assess vo-



cational interventions for those with long-term mental illness.

NIDRR has funded three Rehabilitation Research and Training Centers (at Boston University, the Thresholds Programs in Chicago, and at Matrix Research Institute) to explore varying aspects of this issue, and each of the three participated in an NIDRR-sponsored Consensus Conference in September 1992 to examine past research findings and future research needs in this area.

Nonetheless, nearly everyone with a long-term mental illness remains unemployed. In the process of prioritizing employment, advocates, providers, and policymakers will need to address a number of central concerns about work for persons with long-term mental illness. This paper attempts to summarize those concerns, for many of them will serve as benchmarks for our progress over the next decade.

## Emerging Issues

*Work itself must be redefined.* Often enough, discussions about the work potential of people with long-term mental illness begin with a question about whether or not the majority of those who want to work can indeed do so. This question is more readily answered positively if the term "work" is redefined, and redefined so that it corresponds to the broader society's changing conception of employment. The older paradigm of work—a 9 to 5 job, 5 days a week, year in and year out, with progress steadily made up the organizational and financial ladder—no longer serves in our society as the only definition of employment. Indeed, work patterns have altered dramatically over the past few decades and now embrace a wider array of work styles. Many people do not work 7 or 8 hours a day, Monday through Friday, either because of personal choice or limited job opportunities. Increasing numbers of workers do not stay in a single job or company or career their whole lives; there is broader recognition of the importance of job mobility, time off, and educational programs to the individual's sense of personal fulfill-

ment; and employers are more willing to allow the supports that some people may need (e.g., child care, leaves of absence, employee assistance program counseling, etc.) in order to make their best contribution to the work force.

It is somewhat anachronistic, it would follow, to only look for work potential in those with long-term mental illness who can survive a 40-hour week for a year or more, although there are many persons with disabilities for whom such a job is just right. Many others, however, will want part-time work, periodic work, or work where they can receive the supports they need to succeed at the job. When work itself is redefined, we can say with confidence that the vast majority of people with long-term mental illness can indeed work.

***VR counselors—who remain dubious about the vocational potential of those with mental illness—need more experience with success.***

*Educating many constituencies about the work potential of people with mental illness must be an ongoing responsibility.* Despite a wealth of research and anecdotal evidence about the work potential of people with long-term mental illness, many of the constituencies that should be promoting work opportunities fail to do so. A concerted effort to build a broad consensus around the importance of work is needed. Thus:

- Mental health professionals—therapists and counselors, case managers and housing specialists, etc.—need to

pay greater attention to their clients' employment aspirations.

- Consumers of services—after years of accepting their counselors' assertions that they can't work—need to be more assertive in exploring their vocational options.

- Family members—who are often quite ambivalent about the challenges of employment—need an exposure to both the possibilities and the rewards of work for their relatives.

- VR counselors—who remain dubious about the vocational potential of those with mental illness—need more experience with success.

- Employers—who are only recently coming to terms with the Americans with Disabilities Act—need education on how to integrate this group into the work force.

- Policymakers—who shape budget priorities and program regulations—need to reassess the impact of their decisions on client work incentives.

A broad review of the work potential of people with long-term mental illness should also include a frank discussion of whether or not those with mental illness *should* work. In addition to offering rehabilitation opportunities, how strongly should counselors, family members, and others encourage work, regardless of the financial or social disincentives that may apply?

*Employment issues should be raised early in the overall rehabilitation process.* Little progress will be made in encouraging clients to pursue vocational options if work opportunities are held in abeyance while therapists and counselors, case managers, and families work on related issues; the nature of long-term mental illness is such that there are almost always therapeutic hurdles to be faced, medication issues

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to be resolved, and housing or financial or social challenges to be met. It has been the habit of the field to insist that all of these problems be solved *before* work issues are addressed. This, of course, has tended to interminably delay both rehabilitation and employment and has only served to intensify the perception (of the client as well as the family and the counselors involved) that the client cannot work. The earlier that work is presented as a priority issue and employment is promoted as an immediate goal, the more likely it will be that the individual will be able to establish a primary identity as a worker. Only in a few cases would such an effort be contra-indicated.

*Individuals who are dually diagnosed—with mental illness and a secondary disabling condition—must also be encouraged to work.* Although there is growing awareness of the numbers of people with psychiatric disabilities who have secondary diagnoses—particularly drug and alcohol abuse problems—the expanding number of programs designed for those with dual diagnoses rarely include a vocational element. One can examine the current literature on mental health/substance abuse co-occurrence and only occasionally see a reference to employment programming. There is an urgent need to insure that the emerging programs for this population also make employment goals central to their operations.

*Employment services that emphasize integration into the workplace should become the standard for replication.* Although the research literature on rehabilitation interventions for people with long-term mental illness is still limited, there is growing evidence that integrated employment, i.e., programs that shift the locus of rehabilitation programming from the sheltered environment of the workshop to the more demanding hurly-burly of actual work environments, succeeds best. Transitional and supported employment programs have risen from the realm of exciting experiments to become proven approaches; yet, these are relatively scarce across the country. While the terms “transitional” and “supported” have very

broad meanings, the principles that underlie the best of these programs—rapid movement into a real job, intensive support for stabilization, and ongoing assistance thereafter—are the critical components.

*Consumers should be playing a broader role within the service delivery community.* There are a number of ways in which the human services sector, and particularly the mental health and VR professions, can shape roles for people with mental illness. First, there must be a concerted effort to insure that jobs within the mental health and VR sectors are available. While not everyone who has had a major mental illness makes a wonderful counselor, job coach, or case manager, many of those who have received services have both the knowledge base and the positive empathy which can be invaluable in assisting others to make the leap to employment. Programs need to examine the formal policies and informal discouragements that have kept them from hiring persons with mental illness into their agencies, and they must insure that the training, supervision, and supports these new hires will require are in place. At the same time, the nation has a number of outstanding consumer-operated and consumer-staffed agencies that offer a wide range of rehabilitation services, and these deserve evergrowing support.

*The disincentives to employment embodied in social welfare and healthcare policies must be removed.* Certainly one of the most widely felt disincentives to employment has been the way in which the Social Security Administration's policies have interacted with the absence of a national healthcare program. Most people dependent upon Social Security Insurance (SSI) or Supplemental Security Disability Income (SSDI) are afraid that if they are successfully employed they will lose their access to the medical services (including behavioral healthcare) essential to their lives in the community. For the most part, the work incentive provisions of the Social Security Act have made these fears unrealistic (most of those with long-term mental illness can retain their Medicaid eligibility long

after the financial benefits run out), but the complex rules that govern the system are little understood and far more needs to be done to insure that consumers, families, counselors, and therapists have a more complete understanding of these rules.

***What is clear is that there is a growing consumer constituency dissatisfied with their options and wary that far too many clients are being steered into dead end jobs.***

*Vocational programs must begin to place clients in better jobs.* Fully three-fourths of the jobs found through transitional and supported employment programs are entry level, often at minimum wage rates and with few healthcare or other benefits. This is unsatisfactory; for employment programming to be successful in the long run, the array of jobs available to people with long-term mental illness must mirror the types of jobs available to the general population. While a strong argument can be made that many clients can utilize entry level positions as steppingstones to more demanding work, it is unclear how many people could (and should) move directly into more intellectually or physically demanding positions. What is clear is that there is a growing consumer constituency dissatisfied with their options and wary that far too many clients are being steered into dead end jobs.



*Advocates for those with mental disabilities should play a stronger role in local economic development activities.* All across the country, communities are focusing upon jobs. From the federal level, where job creation strategies are a priority of the current administration, to the state level, where the taxing strategies of one state to attract business vie with economic incentives in another state, the nation is concerned about putting its people to work. Advocates for those with psychiatric disabilities should be a part of these larger discussions about the economy, seeking to insure that the jobs developed are equally or competitively available to people with mental illness.

*Federal and state policies must begin to frame appropriate financial strategies to fund long-term supports for the working client.* Those with long-term disabilities require long-term supports. Although this would seem a prerequisite for the success of programs serving people with periodic and episodic recurrences of mental illness, current policies nonetheless have not been able to assure those who do work will have the ongoing supports they may need. The rate of job loss among those with long-term mental illness is high, and the loss of one job typically results in a decision to either drop out of the job market or to re-enter the VR system.

There are alternatives: It may be possible for ongoing support to help the individual avoid job loss altogether; or, for those who do lose jobs, short-term help in finding another job may permit the individual to quickly re-enter the job market, rather than to re-enter the VR system. The goal of the vocational programs is not so much to help the individual to keep a single job as it is to help the worker with psychiatric disability to establish a long-term attachment to the labor market, to insure that those with long-term mental illness have a growing and strengthening sense of themselves as workers.


Unfortunately, there is little consistent financial support for the kind of job coaching (on or off the job) that many people will need in order to form that attachment, and many

agencies are hard pressed to find fiscal support for long-term services. In a very fundamental way, we continue to make employment a second class priority.

## Conclusion

The agenda is, as usual, a crowded one: professional and consumer education, the removal of financial disincentives, the restructuring of programs and policies, and the develop-

ment of the financial resources for long-term support are all critical aspects of a genuine effort to assist persons with long-term mental illness to work. The growing emphasis within both the mental health and vocational rehabilitation professions on the importance of consumer-directed services will remain little but a phrase unless those systems become more responsive to the most pressing and fundamental requests from consumers for jobs. **ER**



There are *many*  
reasons to hire people  
with disabilities.  
*THIS ISN'T ONE OF THEM.*

RJR  
NABISCO

Hire disabled people for their qualifications, such as their skills, education or experience. After all, people with disabilities just want the same opportunities and treatment as anyone else.



G I V E   A B I L I T Y   A   C H A N C E



# Improving Service Systems Through Systems Integration: The ACCESS Program

Frances L. Randolph, Dr. P.H.

In 1990, the Federal Task Force on Homelessness and Severe Mental Illness—with representatives from the Departments of Health and Human Services, Housing and Urban Development, Labor, Education, Veterans Affairs, and Agriculture—was convened to develop a national agenda to end homelessness among people with serious mental illness. In 1992, their findings and recommendations were published in *Outcasts on Main Street. Report of the Federal Task Force on Homelessness and Severe Mental Illness*.<sup>1</sup> The Task Force acknowledged that many of the services that homeless people with serious mental illness require are inadequately financed and in short supply. In addition, services are provided by various public and private agencies, many with their own area of specialty, financing sources, eligibility requirements, geographic target, and procedures for operating. To obtain access to services, people who are homeless and seriously mentally ill have to overcome enormous barriers created by these complicated and fragmented bureaucracies. For this reason, they are likely to fall between the cracks and receive fewer services than other special-need populations.

About one-third of single adults who are homeless have serious mental illnesses. While they are a diverse group, they share certain characteristics that contribute to their becoming and remaining homeless. They tend to be poor, unemployed, uneducated, members of racial and ethnic minorities, have few or tenuous social ties, and have frequent contact with the criminal

justice system. More than half have co-occurring alcohol or substance abuse disorders.

In an effort to help these people to move from the streets into permanent housing and receive all of the services and supports they need to keep that housing and live a fulfilling life, the task force recommended a national demonstration program that would identify innovative approaches to developing integrated systems for insuring that comprehensive services are available, accessible, appropriate, and accountable for homeless people with serious mental illness.

## The ACCESS Program

The ACCESS (Access to Community Care and Effective Services and Supports) Program, a 5-year demonstration program administered by the Homeless Programs Branch of the Center for Mental Health Services (CMHS), was initiated by CMHS in response to this recommendation. The long-term goal of the ACCESS Program is to foster enduring partnerships that will improve the integration of existing federal, state, local, and voluntary service systems to homeless people with serious mental illness, particularly those with co-occurring alcohol or other substance abuse disorders. The more immediate goal is to identify promising approaches to systems integration and to evaluate their effectiveness in providing services to this population. In September 1993, nine states were awarded approximately \$17 million in cooperative agreement grants for 18 communities to test systems reform strategies that encourage coop-

eration among different levels of government and voluntary organizations to eliminate service fragmentation. Similar amounts were awarded to these states in September 1994, and comparable levels of funding are expected through 1998.

The states and localities receiving funds are: Bridgeport and New Haven, Connecticut; two communities in Chicago; Sedgwick and Shawnee counties in Kansas; St. Louis and Kansas City, Missouri; Mecklenburg and Wake counties in North Carolina; two communities in Philadelphia; Austin and Fort Worth, Texas; Richmond and Hampton/Newport News, Virginia; and two communities in Seattle, Washington.

The two communities in each state were matched on selected demographic and economic variables. To test the effectiveness of different integration strategies, CMHS randomly assigned the two communities within each state to either an integration or a comparison condition. Both communities within each state receive similar levels of service funds to provide assertive outreach and case management. In addition, the integration community receives additional funds to demonstrate different integration strategies. An important component of the ACCESS Program is a national evaluation which is comparing the integration and comparison communities within each state and across all nine states. The system-level evaluation will identify the different systems integration approaches, document how they are implemented, and measure their impact on system capacity and system barriers. The client-level evaluation will determine whether systems integration efforts result in improved



service delivery; improvements in mental health and health status, rehabilitation, quality of life; and permanent exit from homelessness.

## Systems Integration vs. Services Integration

The concept of *systems* integration is often confused with the concept of *services* integration. The goal of services integration is to maximize an individual's use of existing resources in order to help that person achieve improved functioning, greater independence, and enhanced quality of life. Case management is an example of a services integration strategy. The case manager helps clients obtain mental health and substance abuse treatments, benefits and entitlements, rehabilitation and health services, dental care, housing, and transportation. In contrast, systems integration refers to establishing linkages with agencies within a system and across multiple systems to facilitate the provision of services to individuals at the local level. Systems integration focuses on reducing barriers, coordinating and improving existing services, and developing new programs to improve the availability, quality, and comprehensiveness of services.

## Examples of Systems Integration Strategies

A variety of innovative strategies is being tested across the nine states, with each integration community demonstrating a combination of these strategies. Multi-agency task forces are being established at the systems level by many of the integration communities to promote alliances among the participating agencies, identify barriers to service delivery, and develop strategies to address these barriers. Some of the strategies include developing uniform assessment, referral, and eligibility processes and creating shared electronic client and resource databases. Other strategies include staff training about the services provided by other agencies (i.e., cross-training), cooperative agreements for sharing or coordinating resources, and collaborative proposals to various funding sources to create new resources.


Several integration communities are creating *one-stop shopping* models. These are multiservice centers where health-care, mental health and substance abuse treatment, housing assistance, rehabilitation services, vocational training, and entitlements are provided in one location. These centers are usually situated in low-demand settings where homeless persons can also find relief from the streets and get a meal and shower.

A *managed care* approach to service delivery is being tested in one community in which homeless people with serious mental illness will be able to choose among a network of affiliated service providers. Contracts and inter-agency agreements are being developed with many service providers to provide a comprehensive range of services, including substance abuse treatment, mental health services, health-care, family support services, and a drop-in center.

## Anticipated Changes

A major goal of the ACCESS Program is to create "any door" access. If communities are successful in creating integrated service systems, any

homeless person with serious mental illness should be able to contact an agency, within or outside of the mental health system, be assessed, and obtain a full complement of services and supports. To accomplish this will require major changes in the way agencies currently operate and interact with one another. All public and private agencies that provide mental health and substance abuse treatment, health-care, housing assistance, rehabilitation, and income supports and entitlements will have to share in the responsibility of providing services to people who are homeless and have serious mental illness. Interdepartmental collaborations will be necessary to develop common goals, share resources, and reduce service barriers. Also, there will need to be authorities designated at the local or state level to provide coordinated leadership for systems integration activities and be held accountable for the results.

Although it will take a number of years to complete this demonstration program, positive results are already occurring. Relationships are being forged with agencies that historically have underserved or ignored this population. In addition, barriers to service delivery are being identified and solutions for overcoming these barriers are being implemented. An evaluation report will be published annually to provide a timely summary of results to date. 

## Note

1. Copies of this report are available from the Center for Mental Health Services, Office of Consumer, Family and Public Information, 5600 Fishers Lane, Room 15-99, Rockville, MD 20857.

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*Dr. Randolph, is ACCESS Director, Homeless Programs Branch, Division of Demonstration Programs, Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, Rockville, MD.*

**Several integration communities are creating "one-stop shopping" models.**



## RSA's Commitment

(Continued from inside front cover)


- projects to expedite VR eligibility determinations, assessment, and placement of individuals who have severe mental illness and who have previously been found ineligible for VR or who did not achieve employment outcomes;
- projects to test the effects of a consumer-designed recreation program on job satisfaction and employment retention for working adults who have severe mental illness; and
- projects to provide intensive functional assessment in real work settings for individuals who have severe mental illness and work-related cognitive deficits.

In 1995, RSA established a priority for *Special Projects and Demonstrations for Transitional Rehabilitation Services for*

*Youths and Young Adults with Serious Emotional Disturbance (SED) or Serious Mental Illness (SMI)*. The purpose of the priority is to support demonstration projects that develop model systems of comprehensive service delivery to youth and young adults with SED or SMI to prepare them for entry into the labor force. RSA expects to fund approximately 10 such projects.

RSA funds rehabilitation training projects that provide both preservice and inservice training to a variety of rehabilitation professionals whose work supports the development of employment opportunities for persons who have severe mental illness. A number of projects focus on training vocational rehabilitation personnel in psychiatric rehabilitation and provide training related to working with individuals who have been di-

agnosed with both substance abuse and mental disorders. Several projects have a regional interagency focus, bringing together personnel from VR and MH agencies, substance abuse programs, community-based providers, and others to provide training on expanding the rehabilitation opportunities for individuals who have severe mental illness.

This issue of *American Rehabilitation* is the last of two consecutive issues devoted to the topic of "Severe Mental Illness" that serve as important components of RSA's continuing efforts to stimulate the improvement and expansion of employment opportunities for individuals who have severe mental illness. I am pleased to introduce this issue and to reaffirm RSA's commitment to these efforts. 

## Everything You Wanted to Know About Spinal Cord Injury

A national database of *Resources on Spinal Cord Injury* has recently been revised and updated. The database contains information on over 500 videos, pamphlets, booklets, and manuals addressing 12 major subject areas relating to spinal cord injury (SCI)—such as coping with SCI, bowel and bladder management, recreational activities, sexuality, employment, accessibility, and home modifications.

A free printed retrieval, limited to TWO subject areas, may be requested FREE OF CHARGE. A compendium of all materials listed in the database, is available for purchase.

To request a free printed retrieval from the database, call or write: Linda Herson, Division of Education, The Institute for Rehabilitation and Research, 1333 Moursund, Houston, TX 77030. Telephone: 713-797-5945.

To purchase the compendium, send your check for \$50.00 (includes shipping and handling) payable to BAYLOR COLLEGE OF MEDICINE to the address above.

The database was developed under the sponsorship of the American Spinal Injury Association at The Institute for Rehabilitation and Research (TIIR), with support from the Education and Training Foundation of Paralyzed Veterans of America. It is currently funded through Grant #H133B40011 to Baylor College of Medicine and TIIR from the National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education.

## Share Helen Keller's Vision

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Design: GTFH, 114 Fifth Avenue, New York NY 10011



# NEW PUBLICATIONS AND FILMS

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## **Cognitive Behavioural Therapy. research, practice and philosophy.**

Brian Sheldon. Routledge, 29 West 35 Street, New York, NY 10001. 281 pages. Softcover, \$18.95.

*Cognitive-Behavioural Therapy* is a comprehensively revised and augmented text, based on Professor Sheldon's previous book, *Behaviour Modification*, but thoroughly expanded and updated to take into account recent developments in social work effectiveness research, psychotherapy, and clinical psychology, as well as the large-scale changes in the organization of social services.

Based on empirical evidence, the book is designed to give a thorough grounding in cognitive-behavioral methods and their application. Professor Sheldon makes a powerful case for the greater use of these therapies in full recognition of the pressures under which social workers have to operate.

The book offers a guide to assessment and therapeutic procedures, including methods of evaluation; a comprehensive review of the latest research on learning and cognition, examining the therapeutic implications of these studies; illustrations of the main methods of helping with case examples from social work practice; and consideration of the ethical implications of such methods as a part of main stream social work.

The author is Director of Applied Social Studies at Royal Holloway College, University of London.

## **Return to Community. Building Support Systems for People with Psychiatric Disabilities.**

Paul J. Carling. The Guilford Press, 72 Spring Street, New York, NY 10012. 348 pages. Hardcover, \$40.00; softcover, \$18.95.

This book provides a comprehensive, practical approach to fully integrating people with serious mental illnesses into the community. Offering all the substantive information readers need to begin organizing for change, the book draws from resources not currently available in the professional literature—the voices of mental health consumers themselves as well as their families. The volume should interest anyone—mental health professionals, people with psychiatric disabilities, family members, policymakers, housing professionals, and employers—concerned with community mental health and public mental health systems. It should also prove useful for graduate and undergraduate students of community counseling, psychology, social work, and psychiatry.

## **The Handbook of Dramatherapy.**

Sue Jennings, Ann Cattanach, Steve Mitchell, Anna Chesner, and Brenda Meldrum. Routledge, 29 West 35 Street, New York, NY 10001. 232 pages. Hardcover, \$59.95; soft cover, \$19.95.

Drama therapy is being increasingly practised in a range of therapeutic settings and is of growing interest to theatre practitioners and teachers. The *Handbook of Dramatherapy* brings together five authors who have considerable experience working in clinical, artistic, and educational fields to provide an easy-to-read introduction to the major models of drama therapy. The authors explain the differences between drama therapy and psychodrama, discuss its relationship with theatre art, look at assessment and evaluation techniques, and argue the need for more appropriate methods of re-

search for this increasingly popular form of therapeutic treatment.

The handbook provides a comprehensive basis for theory and practice and should be an invaluable resource for all mental health professionals as well as for students of drama therapy and theatre.

## **Music Therapy. An Art Beyond Words.**

Leslie Bunt. Routledge, 29 West 35 Street, New York, NY 10001. 213 pages. Softcover, \$19.95.

Music therapy is a relatively new discipline; although the power of music to alleviate illness and distress has been recognized for centuries, it is only in the twentieth century that systematic research into the reasons for its efficacy has really begun. The author uses this book to explain the purposes and techniques of music therapy as it is practised today to a wide audience of mental health professionals—not just music therapists—and for all those interested in the use of creative arts in therapy.

After setting the development of music therapy in its historical context, and looking at its relationship with other forms of therapeutic intervention, he goes on to discuss, with practical examples, the particular contributions of the different elements of music (such as pitch, rhythm, timbre) to the therapeutic process. From this sound basis of understanding the reader is then easily led into the clinical chapters of the book describing detailed practice with both adults and children in schools, hospitals, and the community. While not failing to acknowledge the creative and emotional power of the medium with which he works, the author makes it clear throughout the book



that a strong research base is necessary if music therapy is to develop its full potential as a therapeutic intervention and that the way forward lies in the successful synthesis of artistic and scientific processes.

The author is a qualified music therapist and is Director of The Music Space Trust and Research Fellow in Child and Mental Health, University of Bristol.

### **Services for People with Learning Disabilities.**

Nigel Malin, editor. Routledge, 29 West 35 Street, New York, NY 10001. 297 pages. Softcover, \$22.95.

This text explores new developments in service provision for people with learning disabilities. An updated version of *Services for the Mentally Handicapped* in Britain (1980), it includes new, additional chapters on current topics, such as advocacy and empowerment, and recreation and leisure.

The contributors focus on linking knowledge of user developments with policy and professional practice in both the statutory and nonstatutory sectors in Britain. They describe the present network of services and explain the NHS and Community Care Act (1990) in terminology accessible to healthcare professionals and others in this area.

With its broad review of available services, *Services for People with Learning Disabilities* should prove an invaluable resource for all practitioners in health and community care.

### **Working with Educational Interpreters.**

Rochester Institute of Technology (RIT), National Technical Institute for the Deaf (NTID), Sign Language and Interpreting Education, Lyndon Baines Johnson Building, 52 Lomb Memorial Drive, Rochester, NY 14623-5604. Telephone: (716) 475-6749 (voice/TTY). \$35.

This is the second NTID videotape in a new series for people who use the services of or hire educational interpreters in schools, classrooms, and other teaching and learning situations in kindergarten through 12th grade.

This captioned videotape describes strategies for classroom teachers and school personnel. The seven-part videotape series details for the consumer expectations and strategies appropriate for working effectively with interpreters.

Although the public school system is the largest employer of educational interpreters in the United States, administrators and teachers currently have limited information on hiring and working with them.

NTID officials are hopeful that this series will break new ground by providing a practical approach for consumers to work effectively with educational interpreters so that all students are provided with optimal communication access throughout their elementary and secondary education.

The videos were shot on location in classrooms across the country. They show educational interpreters practicing their profession in various learning situations and working with students who have different communication and learning needs. The scenes highlight the diversity of interpreting needs and the importance of hiring trained and qualified interpreters.

Last May, this videotape received a third place "Certificate for Creative Excellence" in the General Education category of the United States International Film and Video Festival, which attracted 1,500 entries from 29 countries.

The third videotape in the series, "Employing Educational Interpreters," will be available this fall.

### **Pain as Human Experience. An Anthropological Perspective.**

Mary-Jo DelVecchio Good, Paul E. Brodwin, Byron J. Good, and Arthur Kleinman, editors. University of California Press, 2120 Berkeley Way, Berkeley, CA 94720. 214 pages. Softcover, \$14.00.

This collection of essays attempts to explore all aspects of the phenomenon we call pain. Topics include *A Body in Pain—The Making of a World of Chronic Pain*, *Work as a Haven from Pain*, *Symptoms and Social Performances: The Case of Diane Reden*, *Chronic Illness and the Con-*

*struction of Narratives*, "After a While No One Believes You": *Real and Unreal Pain*, and *Pain and Resistance: The Delegitimation and Relegitimation of Local Worlds*.

### **The History of Special Education. From Isolation to Integration.**

Margret A. Winzer. Gallaudet University Press, Kendall Green, Gallaudet University, 800 Florida Ave. NE, Washington, DC 20002-3695. Telephone: 1-800-451-1073. 463 pages. Hardcover, \$55.95.

This book traces the painfully long path through Western Europe, the United States, and Canada toward the realization of equitable opportunities for disabled students. Readers might be familiar with the treatment long ago of deaf, blind, and mentally and physically disabled people when, if they were not vilified publicly, they were locked away. However, biases practiced in this century recounted here might seem more surprising if not shocking; these include "scientific" explanations for disabilities that justified limited expectations and resources and even sterilization.

This comprehensive volume breaks new ground in assessing the development of special education as a formal discipline from the first efforts in early Christian times to such current mandates as Public Law 94-142.

This book presents a four-part narrative that describes the emergence of this branch of education in fascinating detail, beginning with the earliest instruction and theories by isolated individuals in 16th century Spain and the effects of the Age of Enlightenment on nascent organizations in 17th century France and England. It joins together the growth of ideas and schools in 18th century Europe and North America with the 19th century consideration, for the first time, of the vital issues of placement, curriculum, early intervention, and the status of teachers. Social trends such as the "medicalization" of the causes of disabilities, "scientific racism" based upon I.Q. tests, and the movement toward integration in all schools are also weighed regarding their effects upon early and latter-day 20th century programs.



The author, who is Associate Professor of Education at the University of Lethbridge in Alberta, Canada, examines every significant figure involved in special education, including Ponce de Leon, Bonet, Diderot, Tuke, Gallaudet, Bell, Howe, Snellen, Jackson, Montessori, Binet, Watson, Dewey, Kirk, and Dunn. She provides insights on the change in sensibilities over time through separate essays that highlight select figures and significant events. Tables tracking notable trends, such as the increase of women teachers, round out this thorough examination.

### **Comparative Studies in Special Education.**

*Kas Mazurek and Margret A. Winzer, editors. Gallaudet University Press, Kendall Green, Gallaudet University, 800 Florida Ave. NE, Washington, DC 20002-3695. Telephone: 1-800-451-1073. 504 pages. Hardcover, \$55.95.*

This book fills the void in recent scholarship in this vital area so that those planning objectives can at last benefit from expert assessments of programs around the world. More than 50 noted scholars in special education describe programs worldwide for all special populations—blind, deaf, physically and mentally disabled, and all others.

This collection provides special educators everywhere with a complete picture of the ongoing research, social experiments, relevant legislation, in-place structures and processes, accepted professional practices, and educational goals and objectives of all regions of the world.

This volume is divided into five sections, each with an introduction to the chapters within. Each section defines the extent of the development of special education in the countries included, such as the limited programs in Papua, New Guinea; Senegal; the West Bank and the Gaza Strip; and South Africa. Section Two describes emerging special education in Nigeria, Brazil, Indonesia, Pakistan, and several other locales. Segregated special education in Japan, Taiwan, Russia, and other countries comprise Section Three, while Sec-

tion Four explores countries that are approaching integration, such as Poland, Australia, and Canada. Integrated special education is depicted in Norway, Finland, Sweden, the United States, New Zealand, and other nations in the final section.

Contributors to this book include David Donald, Barend Vlaardingerboek, Alphonse Pu, Sabou Sarr, Theresa B. Abang, Lucia G.V. Dellagnelo, Xu Yun, Marie Cerna, Wladyslawa Pilecka, David Mitchell, and the editors themselves.

### **Health Care for the Poor and Uninsured.**

*Nellie P. Tate and Kevin Kavanaugh, editors. The Haworth Press, Inc., 10 Alice Street, Binghamton, NY 13904-1580. 98 pages. Hardcover, \$24.95.*

This book, which focuses on the promotion, coordination, and financing of healthcare services for poor and uninsured people, describes techniques to promote access to health services, innovative approaches to public/private collaboration in the delivery of services, financial strategies of health maintenance organizations, and the formation of foundations to fund healthcare delivery. Although the studies in the book are of successful programs for pregnant women, infants, and children—groups often in the greatest need—the strategies incorporated by these programs are easily adapted to serve other populations.

Some of the topics addressed in this guide include:

- effective use of nurse practitioners and mid-wives to provide prenatal care;
- a description of referral systems which promote the coordination of public and private sectors;
- hospital financial support of state screening programs;
- aggressive outreach programs to reach special populations;
- factors influencing family selection of a healthcare provider;
- new approaches to funding long-term care; and
- the use of outreach clinics and a coordinated referral system.

### **Back to Work. How to Rejoin the Workforce After an Absence.**

*Dr. Laurence Lipsett. Curtice Publishing Company, 207 Curtice Park, Webster, NY 14580-3422. 98 pages. Softcover, \$15.95 plus shipping.*

For homemakers, veterans, persons with disabilities, and unemployed persons, this book is designed to make the quickest re-entry for people who need immediate employment. It details how to write resumes and letters and how to sell yourself in an interview. For career planning, this book shows how to relate your interests and abilities to jobs, where to get career counseling, and how to decide about returning to school.

### **Practising Social Work.**

*Christopher Hanvey and Terry Philpot, editors. Routledge, 29 West 35 Street, New York, NY 10001. 207 pages. Hardcover, \$59.95; softcover, \$16.95.*

This text provides a systematic exploration of a range of social work approaches, with each chapter focusing on a single theme and explaining the practice implications of particular methods. It takes in a range of client groups, from young offenders to elderly people, and covers many aspects of social work, including antiracist work, a feminist approach, working with service users, crisis intervention, alternatives to custody, and family therapy.

### **Researching the People's Health.**

*Jennie Popay and Gareth Williams, editors. Routledge, 29 West 35 Street, New York, NY 10001. 209 pages. Softcover, \$18.95.*

This book examines two related issues: the role of social research in the rapidly changing world of health services and the relationship between lay and expert knowledge in public health and healthcare. It makes a contribution to the continuing and urgent debate on the assessment of health needs, the organization and delivery of healthcare, and the politics of health services organization and funding.



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# AMERICAN Autumn–Winter 1995 REHABILITATION

75<sup>th</sup> Anniversary Issue





# A History to be Proud of: 75 Years of Vocational Rehabilitation

Seventy-five years ago, the Smith-Fess Act created the vocational rehabilitation (VR) program, which is one of the oldest grant-in-aid programs to states. Since its creation in 1920, VR has enjoyed bipartisan congressional support and has been continually reauthorized because of its record as a strong, cost-effective service delivery program that produces documented results.

The VR program was established with a small budget and was limited in scope to providing counseling, training, prostheses, and placement services to individuals with physical disabilities. Today, with a budget of more than \$2 billion, the VR program can provide a complete array of services to all disability groups.

The program has a history of positive, creative change. In 1943, its scope was expanded to include physical restoration services. Additionally, VR services were extended to individuals with cognitive impairments, including persons with mental illness.

In 1954, the program was again augmented by the inclusion of private community-based rehabilitation programs and authorization for necessary program supports such as rehabilitation research and demonstration activities, training of rehabilitation professionals and the establishment and improvement of community rehabilitation programs.

In 1965, the program was further expanded to assist individuals who were disabled by the lack of educational and social skills.

A major change in VR legislation took place in 1973 with the passage of the Rehabilitation Act as we know it today. This change charted a new course for the VR program by giving priority for services to individuals with severe disabilities. A significant expansion occurred again in 1986 with amendments to the Rehabilitation Act of 1973 that authorized the supported employment program.



*Commissioner Fredric K. Schroeder*

Another significant reinvention of the VR program took place in 1992 with major amendments to enhance the role of individuals with disabilities in directing their own rehabilitation programs. This formed the basis on which individuals with disabilities were to be full partners with rehabilitation professionals. The 1992 Amendments also mandated that all individuals would be presumed to benefit from VR services in terms of employment unless it could be demonstrated that clear and convincing evidence existed to rebut this presumption. The 1992 Amendments also made a number of other program and administrative changes to strengthen the program.

The VR program has evolved significantly during its 75-year history. Approximately 9 million people with disabilities have been assisted in acquiring gainful employment. More than 1.2 million people with disabilities are served annually and 200,000 people

*Continued on page 42*



# AMERICAN REHABILITATION

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Autumn/Winter 1995

The weakest ink is better than the strongest memory.

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# The Changing Universe of Disability

***This 75th anniversary of rehabilitation is an opportunity to celebrate the past and to contemplate the future. The accomplishments of the past in rehabilitation and disability advocacy, in services and research services, affords a backdrop to analyze current trends and a foundation to plan for the future. The emerging issues identified in this article are intended to assist consumers, researchers, and service providers in their planning activities.***

*Katherine Seelman, Ph.D.  
Sean Sweeney, Ph.D.*

**I**ncreased life expectancy and new scientific and technological innovations have added new segments to the traditional disabled population. For example, more and more people are living into old age with disabilities acquired in childhood and are now experiencing secondary conditions of disabilities. In addition, people with disabilities are continuously challenging the accessibility of the social and physical environment, have become part of the leadership, and are increasingly involved with researchers and services providers to shape their future. Clearly, these changes are monumental and suggest a new agenda in areas such as participatory action research, leadership development, community integration, health, architecture, engineering, and telecommunications.

But the face of the disabled population is changing. This article focuses on several different and rapidly emerging challenges to rehabilitation and disability practitioners.

In late 1967, the Council of State Administrators of Vocational Rehabilitation (CSAVR), and later other groups, argued that the rehabilitation field should play "a more direct and active role in restoring the disadvantaged." While the language may be dated, the message is current. As the descriptive information in this article suggests, poverty is the primary screening indicator of the many variables that increase the risk of disability. At the time of the CSAVR report, the significance of societal changes in creating new disabled populations was not as apparent as it is today. But these emerging causes of disability will have tremen-

dous impact on the professionals providing and the populations requiring special education, social and rehabilitative services, and community integration of services. Attention to what may be an emerging universe of disability is also warranted by the dramatic increase in the number of young people on Supplemental Security Income (SSI) and Social Security Disability Income (SSDI). Between 1990 and 1995, federal expenditure for SSI and SSDI increased from \$35.2 billion to \$65.4 billion.

The expanding or new universe of disability is resulting from changing causes and patterns of disabilities which include but are not limited to such conditions as (1) violence and abuse, (2) aging, (3) substance abuse and stress, (4) inadequate prenatal care, (5) low birth weight, (6) adolescent pregnancy and childbearing, (7) poor nutrition, (8) environmental/toxic exposures, such as alcohol, smoking, drug abuse, and lead, (9) sexually transmitted diseases, including pediatric HIV and Aids, (10) injuries, and (11) child abuse and neglect. Researchers need to identify and describe these populations in terms of socioeconomic, education, ethnic/cultural, geographic, and other factors and by the disability related consequences, including functional loss, employment, and social behavior.

About 38 million Americans—15 percent—report having some activity limitation due to chronic health conditions: 4.6 percent of the population are unable to perform their major activity, 5.7 per-

---

*Dr. Seelman is Director of the National Institute on Disability and Rehabilitation Research (NIDRR); Dr. Sweeney is a Rehabilitation Analyst and Gerontologist with NIDRR.*



cent are limited in the amount or kind of major activity they can perform, and 4.7 percent are limited in activities other than their major activity (National Center for Health Statistics, 1992). Of the population aged 18–68, 11.6 percent, or 19.0 million people, report some degree of limitation in working at a job or business due to chronic health conditions. This group includes 6.6 percent of the working population, or 10 million people, who report being unable to work at a job or business. An additional 3.9 percent of working-age persons are limited in activities other than working at a job or business. By these measures alone, disability ranks as the nation's largest public health problem, affecting not only individuals with disabling conditions and their immediate families, but also society at large. Many medically, socially, and economically important issues call attention to the need for developing an effective national disability prevention program. One is modern medicine's progress in prolonging life, or, more accurately, averting deaths. For example, the odds of survival for low birth weight babies have increased steadily during the past several decades. The age-adjusted rate of deaths caused by injuries has fallen precipitously, from 57.5 deaths per 100,000 injuries in 1950 to 29.4 deaths per 100,000 injuries in 1986 (National Center for Health Statistics, 1992). Medical victories, however, do not always translate into absolute victories. The outcome of surviving prematurity, injury, heart attack, or stroke may be disabling conditions that can result in a diminished quality of life and the need for continuing supportive services. Because assessments of the nation's health are based largely on mortality statistics, U.S. society rarely reckons with the full consequences of extending lives. As the number of people who survive life-threatening conditions increases, quality of life issues must be given fuller consideration in health and social policy decisions.<sup>1</sup>

Disability imposes an enormous economic cost on society. It is costly to the nation in terms of the medical resources used for care, treatment, and rehabilita-

tion; in reduced or lost productivity; and in premature death. For example, people with disabilities use more medical care services than those without them. In 1987, 17 percent of the noninstitutionalized population that was limited in activity due to chronic conditions made 19 percent of the visits to physicians and accounted for 38 percent of the hospitalizations. Persons with activity limitations made 20 physician visits per person, compared with about 3.9 visits for persons with no activity limitation (National Health Interview Survey, 1989). Lack of insurance coverage also affects physician contacts. Uninsured adults unable to perform their major activity have 25 percent fewer physician contacts than those with insurance—15.6 versus 20.9 contacts. Among adults not limited in activity, physician contacts are 47 percent fewer for those without insurance than for those with insurance—2.3 versus 4.3 contacts.<sup>2</sup>

*The income level for people with disabilities is substantially lower than that of nondisabled people.*

## Poverty

Poverty, while not an independent factor in morbidity, nonetheless acts as a proxy for many of the variables that in turn increase the risk of disability. Inadequate prenatal care, single teenage pregnancy, poor nutrition, and low educational attainment, while not exclusive to any one segment of society, are more readily encountered among the poor. While poverty can touch anyone, the ranks of the poor are mainly those of women and children. After the child is born, the environment he/she grows up in can have a profound influence on cognition and physical and psychosocial development. Environmen-

tal stress, inadequate medical care, and the possibility of emotional and physical abuse are all exacerbated in socially disadvantaged environments.<sup>3</sup>

The income level for people with disabilities is substantially lower than that of nondisabled people. People below the poverty line have a 21.3 percent rate of limitation, compared to 13.3 percent for those above the poverty line. The average household income for the general population in 1988 was \$34,017 per year. In contrast, the median family income for people with disabilities was around \$18,000. A comparison of the two income levels shows that the income levels of people in the general population exceed that of people with disabilities by as much as 47 percent. When examined according to race, it is evident that white persons with disabilities are generally in the low income ranks (\$18,000), but not as destitute as Hispanics (\$12,000) or African Americans (\$8,000), whose family income levels fall below the poverty index reported in the latest census (\$12,091). The situation is especially acute for African Americans with disabilities where income lags behind those of whites with disabilities by at least \$10,000 per year. In addition, people in the general population have income levels which more than quadruple those of African Americans with disabilities. Overall, it appears that income levels for African Americans with disabilities are markedly lower than those of people who are not disabled, whites with disabilities, and Hispanics with disabilities. By the same token, white people with disabilities are also far below income levels of the nondisabled population.<sup>4</sup>

## Violence and Abuse

Violent and abusive behaviors continue to be major causes of death, injury, and stress in the United States. Suicide and homicide have resulted in over 50,000 deaths annually between 1985 and 1991 and victims of violence have exceeded 2 million people annually. Violence produces extensive physical costs and emotional consequences for society. The widespread nature of these consequences may indicate that vio-



lence has become a routine part of social interaction in many domestic settings. It may also become a mode of behavior adopted by future generations raised in such settings.<sup>5</sup>

At the cultural level, acceptance of physical violence to resolve conflicts contributes to the acceptance of abuse. Societal influences include policies that fail to protect children or fail to effectively address problems that contribute to abuse and neglect (e.g., poverty, unemployment, inadequate educational opportunities). Parental rights to privacy and autonomy in child raising resist interference by society even when their practices injure, disable, or cause the death of their children. At the community level, crowded housing and inadequate community supports are associated with a higher incidence of maltreatment. Neighborhood violence and other forms of family violence also contribute to child abuse.<sup>6</sup>

Disabilities can be caused and/or exacerbated as a function of abuse. Recent studies suggest that up to 25 percent of abused children may retain permanent disabilities as a direct result of abuse. Approximately 52 percent of neglected children may suffer permanent disabilities. This is not difficult to understand, once we consider the impact of head trauma and malnutrition, the primary contributors to this problem. Head trauma, caused by blows to the head, shaking the child, throwing the child, or other means, often results in permanent brain damage. Other actions that cause brain damage include those that stop oxygen from getting to the brain, such as suffocation and attempted drowning. Damage to the brain can cause permanent intellectual difficulties as well as neurological problems, including learning disabilities, mental retardation, memory problems, speech and language problems, blindness, deafness, epilepsy, motor impairments (i.e., cerebral palsy), and plegias (i.e., para or quadriplegia). Disabilities resulting from abuse have profound effects on multiple areas of functioning, including economic, social, educational, religious, medical, and vocational realms.<sup>7</sup>

Less direct consequences of violence may be delayed or cumulative. The stress induced by violent acts, especially when repeated within an intimate relationship, may culminate in severe emotional trauma or physical illness. Stresses may also accumulate for communal organizations. Although the cumulative effects of violent crime on neighborhood cohesion and public services are not easily measured, they are substantial for some communities. Delayed effects occur in even less obvious ways.

***Domestic violence, spouse abuse, child abuse, child sexual abuse, and elder abuse are the more common manifestations of violence in our communities today.***

The intergenerational transmission of violent behavior by physically abusive parents, siblings, and caregivers, for example, is a delayed cost, as new generations of violent people inflict physical harm on their families and others in the community.<sup>8</sup>

Domestic violence, spouse abuse, child abuse, child sexual abuse, and elder abuse are the more common manifestations of violence in our communities today. The Department of Justice reported that there were at least 4.1 million cases of family violence between 1973 and 1981, or an average of 450,000 per year (Department of Justice 1984). The department added, in its "Special Report on Family Violence," that the reported figure "was probably significantly lower than the actual number of cases since these estimates reflect only behavior that victims are willing to label as criminal and report to survey interviewers" (Department of Justice 1984).<sup>9</sup>

Nearly one-third of the 19 million crime victimizations reported to the NCS in 1990 involved violence. The prototype violent crime is an assault. Aggravated assaults, those with weapons or causing serious nonfatal injury, accounted for nearly 300 of every 1,000 violent victimizations. Less serious simple assaults accounted for more than 500. Robbery accounted for most of the rest. Forcible rapes accounted for about 20 in every 1,000; fewer than 4 in every 1,000 violent victimizations resulted in death for the victim.<sup>10</sup>

## **Minorities and Violence**

African Americans are disproportionately represented in all arrests, and more so in those for violent crimes than for property crimes. In terms of violent crimes, African Americans constitute 45 percent of all arrestees. They are most overrepresented in the most serious violent crimes of homicide, forcible rape, and robbery. Particularly striking is their substantial overrepresentation in the crime of robbery, a crime that is both a person and a property crime.<sup>11</sup>

In 1990, African Americans were 41 percent and Hispanics 32 percent more likely than whites to be victims of violent crime. Ethnic differences combine with age and gender patterns so that young African American males recently have been about 20 times more likely than older white females to be victimized. Homicide rates are also highest for minorities: The African American rate is 5 times the white rate, and rates for Native Americans about double the rate of the entire population.<sup>12</sup>

Death by homicide among white males is 7.9 per 100,000. For African American males, the rate is 58.1. For white females, to whom gun manufacturers target much of their sales, it is 2.9; for African American females, 13.2.<sup>13</sup>

Homicide was the leading cause of death among African American youth (77.9), for whom the rate in 1989-91 was eight to nine times those for white (9.6) and Asian youth (8.8). Hispanic youth, for whom the rate was more than three



times that for white youth, had the second highest homicide rate (30.5).<sup>14</sup>

Homicide was the second leading cause of death for African American adults 25–44 years of age, with a rate that was nearly seven times that for white adults. The second highest death rate for homicide was for adults of Hispanic origin, for whom the rate was nearly three times that for white adults.<sup>15</sup>

Homicide was the second leading cause of death among African American children. In 1989–91 the homicide rate for African American children (5.2) was two to four times the rates for children of other groups.<sup>16</sup>

In 1989–91, the death rate for African American youth 15–24 years of age (161.9 deaths per 100,000 population) was 81 percent higher than the rate for white youth (89.3). The death rate for American Indian youth (142.0) was 59 percent higher than that for white youth. Youth of Asian ancestry had the lowest death rate (50.1), 44 percent below that for white youth.<sup>17</sup>

## Children and Violence

All types of abuse are found in children with disabilities. It is generally believed that children with disabilities are abused more frequently than their generic counterparts. However, several investigations suggest that children with disabilities may be maltreated at a rate between 4–10 times that of the generic

population. Such conclusions are primarily based upon retrospective studies of samples of abused children, which show incidence rates of disability between 3 and 70 percent. Retrospective studies of samples of children with diverse disabling conditions yield equally high variable findings, with maltreatment rates of 3 percent to 39 percent.<sup>18</sup>

Social status (measured by family income) is substantially related to children's risk of injury from abuse and neglect. For children from families with incomes less than \$15,000, the rate of physical abuse was three and one-half times greater and the rate of sexual abuse six times greater than for other children. The general pattern that physical abuse was more frequent than sexual abuse held for both high and low income families (Sedlak, 1991a,b). Moreover, the seriousness of injury or impairment was substantially related to family income: The rate of serious injury was almost seven times greater, of moderate harm nearly five times greater, and of probable injury seven times greater for children from lower income than from higher income families (Sedlak, 1991a,b).<sup>19</sup>

The U.S. Advisory Board on Child Abuse and Neglect estimates that in 1989 at least 1,200 and perhaps as many as 5,000 children died as a result of maltreatment and over 160,000 children were seriously harmed (U.S. Department of Health and Human Services, 1990:15).<sup>20</sup>

Clinicians have been impressed with the frequency with which child abuse and spouse abuse occur together. Gayford (1975) reported that 37 percent of the women and 54 percent of the men who had been abused beat their children; Hilberman and Munson (1977–78) identified physical and/or sexual abuse of children in a third of the families they studied. Emotional neglect, abuse, alcoholism, and frequent separations were the norms and children in violent homes were witnesses and targets of abuse (Gayford 1975; Gelles 1974; Hilberman & Munson 1977–78; Scott 1974; Walker 1979).<sup>21</sup>

## Women and Violence

The incidence of sexual abuse among women in general has been fairly well documented; however, only a few studies have examined the incidence among women with disabilities. The DisAbled Women's Network of Canada surveyed 245 women with disabilities and found that 40 percent had experienced abuse, 12 percent had been raped. Perpetrators of the abuse were primarily spouses—including ex-spouses—(37 percent) and strangers (28 percent), followed by parents (15 percent), services providers (10 percent), and dates (7 percent). Less than half were reported, due mostly to fear and dependency.<sup>22</sup>

Each year in the United States, 3 to 4 million women are assaulted in their homes by their husbands, former husbands, boyfriends, or lovers. This includes approximately 1.8 million women living with a man and an equal number who are single, legally separated, or divorced. Another 3 to 4 million women have been beaten in the past and remain in abusive relationships.<sup>23</sup>

There have been three U.S. surveys of representative samples specifically designed to determine rates of interpersonal violence in families. In the only national survey, Straus et al. estimated that 3.8 percent, or 1 of every 26 American wives, were beaten by their husbands in the sample year, or a total of almost 1.8 million. An estimated 12.6 percent of all couples (1 out of 8, or 6 million couples)





reported at least one abusive episode in the course of their marriage.<sup>24</sup>

Two state surveys report higher rates. A Harris poll found that 10 percent of Kentucky housewives had experienced spousal violence during the year and 21 percent reported they had been beaten at some point in their marriages. A survey of 2,000 female residents of Texas revealed that 8.5 percent of women had been physically abused in a single year and that 29.7 percent of all women surveyed had been physically abused at some time.<sup>25</sup>

Unlike the other surveys, the Texas study was not limited to married or intact couples. Extrapolating from its findings, we estimate that between 4 and 5 million women are beaten in the U.S. each year (approximately 8 percent) and perhaps three times this many, between 12 and 15 million, have been beaten in the past.<sup>26</sup>

## Elder Abuse

Although the rates of victimization among people aged 65 years and over are lower than those in the younger population, the physical, psychological, and financial consequences may be more serious and often life threatening. Particularly disturbing is the realization that many older people are victimized in their own homes by family members.<sup>27</sup>

According to the report, *Elder Abuse: A Decade of Shame and Inaction*, released in May 1990 by the Subcommittee on Health and Long-Term Care of the Select Committee on Aging of the U.S. House of Representatives, "about 5 percent of the nation's elderly may be victims of abuse from moderate to severe." The report further suggests that "about 1 out of every 20 older Americans, or more than 1.5 million people, may be victims of such abuse each year." Similarly, the National Aging Resource Center on Elder Abuse (NARCEA) es-

timates that nearly 1.57 million older people became victims of domestic elder abuse during 1991.<sup>28</sup>

Federal definitions of elder abuse, neglect, and exploitation appeared in the 1987 amendments to the Older Americans Act. These definitions are guidelines for identifying the problems. Broadly defined, there are three basic categories of elder abuse:

- domestic elder abuse;
- institutional elder abuse; and
- self-neglect or self-abuse.<sup>29</sup>

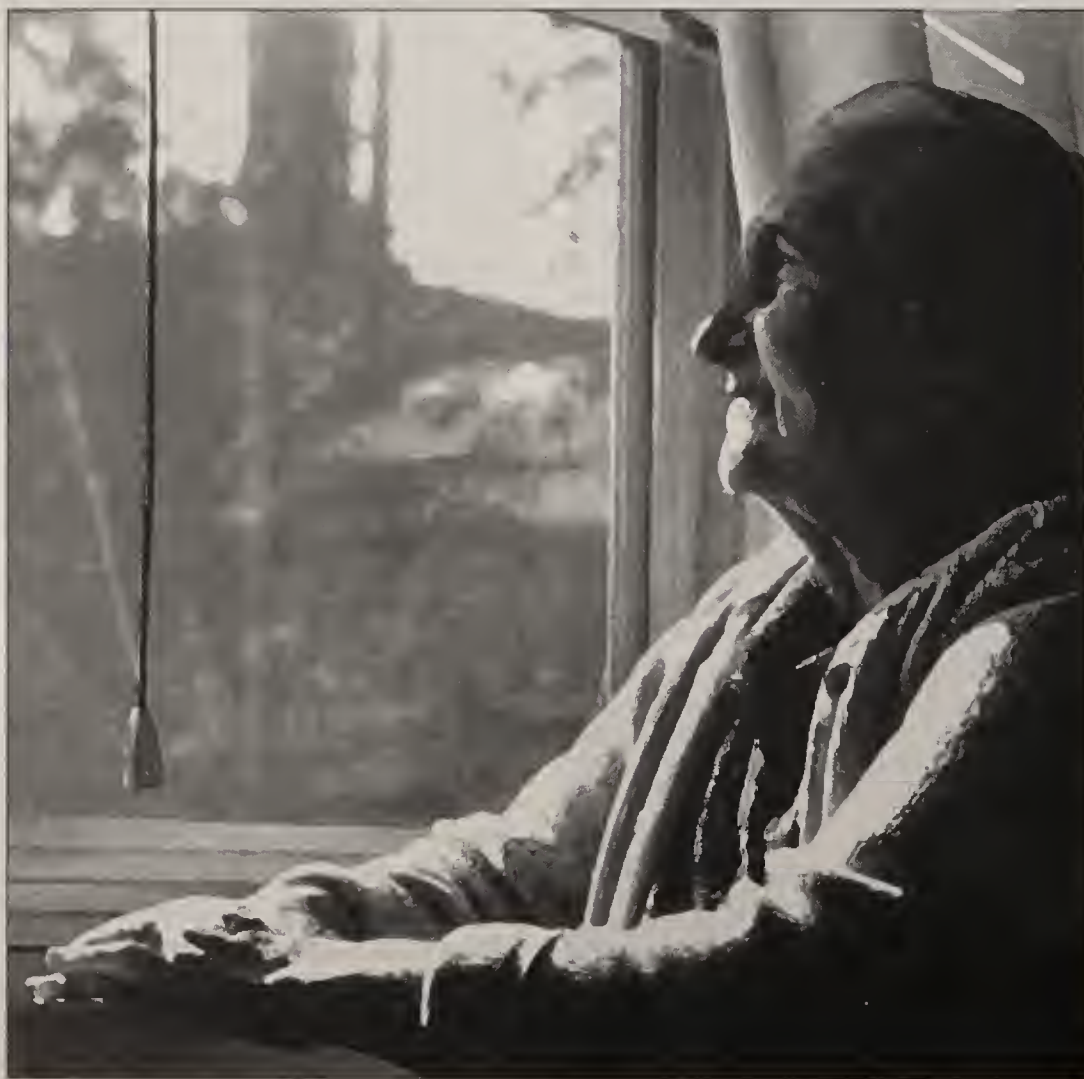
Neglect is the most common form of elder maltreatment in domestic settings. Of the domestic elder abuse cases that were substantiated in 1991, 45.2 percent involved neglect. Physical abuse accounted for 19.1 percent in the same year, while financial/material exploitation was 17.1 percent of the substantiated reports.<sup>30</sup>

Adult children are the most frequent abusers of the elderly in domestic settings. For example, 32.5 percent of the substantiated elder abuse cases in 1991 involved adult children as abusers. Spouses ranked as the second most frequent abusers (14.4 percent) and "other relatives" (12.5 percent) followed closely behind spouses in the same year.<sup>31</sup>

According to the General Accounting Office (GAO) study, about 80 percent of the estimated 6 million dependent elders in this country are cared for at home. Among them are many severely disabled older people who suffer from mental or physical disabilities, or both. Generally, researchers have found that elders in poor health are more likely to be abused than those in good health.<sup>32</sup>

## Alcohol and Violence

There are fewer empirical studies of the relationship between drinking and sexual assault than studies of the relationship between drinking and homicide and nonsexual assault. In some ways, however, the findings are very similar: the victim, the offender, or both were drinking in a substantial percentage of sexual assaults. Most studies estimate that between one-third and three-quarters of sexual assaults in-





volve alcohol consumption by either or both participants.<sup>33</sup>

Hotelling and Sugarman (1986) analyzed risk factors associated with husband-to-wife violence in nine studies that included some kind of comparison group. Alcohol was found to be a significant risk factor for husband-to-wife violence in seven of the studies. In a review of several studies that focused on drinking or problem drinking as factors in marital violence, Frieze and Browne (1989) found that alcohol problems were common among spouse abusers. They also found that incidents of spouse abuse were often unconnected with drinking and that spouse abusers who were also problem drinkers tended to have problems in addition to their drinking.<sup>34</sup>

## Substance Abuse

Rehabilitation outcomes may be influenced profoundly by substance abuse. Unrecognized and untreated substance dependence is likely to interfere with the intensive physical, vocational, and psychological adjustment required following a disability and injury. Reliable predictors of future chemical dependence problems among people with disabilities will be essential for improving patient care and rehabilitation planning. The problems of addiction and disability combine not additively, but exponentially, and thus create a need for a special responsive and innovative approach to intervention. The increased focus on alcohol and other drug abuse and disabilities is timely. Recent studies suggest that a person with a disability is at higher risk for alcohol and other drug abuse problems. For example, alcohol and other drug abuse rates for people with disabilities may range from 15 to 30 percent of all people with disabilities. Alcohol and other drug abuse rates for people with certain disabilities such as spinal cord and head injury exceed 50 percent of those populations (Heinemann et al., 1989; Sparadeo and Gill, 1989). These figures are considerably above the national average.<sup>35</sup>

Clearly, people with disabilities may abuse alcohol and other drugs for all the same reasons as their nondisabled peers. However, the higher risk reflects a number of other reasons directly related to the existence of a disability. These include: medication; health concerns; chronic pain; peer group differences; increased stress on family; fewer social supports; enabling of alcohol and other drug use by others; excess stress time; and lack of access to appropriate alcohol and other drug abuse prevention resources.<sup>36</sup>

An increase in the number of women using cocaine, particularly those women of childbearing age, has contributed to an increase in the number of drug-exposed newborns. According to a 1988 nationwide survey of 36 hospitals, the overall rate of newborns exposed to maternal substance abuse was at least 11 percent, affecting approximately 375,000 children annually. The Select Committee on Children, Youth and Families recently surveyed 18 Metropolitan hospitals, 15 of which reported three to four times as many drug-related births today as in 1985. A recent study of maternal cocaine and heroin use reported that 85 percent of mothers who admitted using cocaine reported using "crack" cocaine (Fulroth, Phillips, & Durand, 1989).<sup>37</sup>

The organic influences of prenatal drug exposure appear to affect emotional development and regulation, social development and relational organization, and cognitive development in the representational and symbolic aspects of play. Problems in later language development can be anticipated. Similarly, cocaine-exposed infants have been characterized as easily frustrated, distractable, and prone to temper tantrums and information-processing difficulties. These difficulties continue to be evident in the preschool years and beyond.<sup>38</sup>

The implications of the long-term neurological problems that manifest themselves at the time the drug-exposed child enters school are disconcerting. We may in fact be creating large numbers of school children with various learning problems who may never

function to their optimal capacity within the school environment, which, in turn, will have grave implications when they reach adulthood.<sup>39</sup>

## HIV Infection

Between 1987 and 1991, the age-adjusted death rate for HIV infection more than doubled, from 5.5 to 11.3 deaths per 100,000 population. During this period, HIV infection increased from 15th to 9th in the ranking of leading causes of death. Provisional data indicate that HIV infection was the eighth leading cause of death in 1992. In 1991, the age-adjusted HIV infection death rate for African American males was more than three times that for white males (52.9 and 16.7 deaths per 100,000) and the rate for African American females was more than nine times that for white females (12.0 and 1.3 deaths per 100,000).<sup>40</sup>

As the number and survival time of people with HIV-related illness grow, the evaluation and treatment of AIDS-related physical disability will become increasingly important. Knowledge of impairments and subsequent disabilities seen in AIDS will be necessary for proper referral to rehabilitation services by primary care physicians and healthcare workers. The AIDS epidemic will significantly impact the practice of rehabilitation medicine (physiatry) in the United States. Appropriate and timely management of physical deficits will be crucial in assuring maximal quality of life and minimal burden of care for families, friends, and healthcare professionals. Physical disability will undoubtedly influence the financing and cost of long-term healthcare in HIV illness.<sup>41</sup>

The projected increases in the number of people with HIV infection and AIDS have been widely reported. By 1995, estimates are that approximately 300,000 people will be living with AIDS (Hellinger, 1992; Vachon, 1993). More than 1 million people are estimated to be HIV seropositive. It has been asserted that people with AIDS are living longer, but perhaps with greater likelihood of disability.<sup>42</sup>



## Children with HIV Infection

We are perhaps facing one of the most serious long-range threats to our children's health. The National Coalition on Prevention of Mental Retardation estimates that in cases of symptomatic pediatric HIV, between 78 percent and 93 percent involve prominent central nervous system damage (Diamond & Cohen, 1987). These children show neurologic abnormalities that include developmental delays, chronic encephalopathy, seizure disorders, motor dysfunctions, microcephaly, and cortical atrophy, along with numerous other

***Low birth weight infants have neurodevelopmental disabilities at three times the rate of normal birth weight babies.***

physiological and psychological symptoms. HIV infection threatens to become the primary infectious cause of developmental disabilities and neurologic impairment in children.

Many of these adverse physical and mental conditions will continue over extended periods of time, especially as these children live longer (Boland, 1987; U.S. Department of Health and Human Services, 1987).<sup>43</sup>

Previously, untreated children sustained high rates of early mortality and often were severely compromised medically, cognitively, and physically prior to death. More than 50 percent of children with HIV infection now live into school age, many with improved functional ability. Another group of children are HIV positive but may not be symptomatic and may not have come

to medical attention. Estimates about the size of this population range from 10,000–20,000. Schools, daycare centers, Head Start programs, and other child service agencies in high-risk HIV areas have begun to presume existence of a population of HIV positive children.<sup>44</sup>

Of children with HIV disease, 75–90 percent show neurodevelopmental delays and neuropsychological deficits. Computerized tomography scans and magnetic resonance imaging (MRI) techniques show "cerebral atrophy with enlargement of the ventricles and subarachnoid space. This change is almost universal in pediatric AIDS and may predate neurologic symptoms."<sup>45</sup>

Approximately 80 percent of infected children have acquired HIV disease from an infected mother during pregnancy. Current research suggests that 30 percent of children born to infected mothers will acquire HIV disease. However, the mechanisms of transmission are not clear at present. It is currently believed that infants may acquire the virus while in utero, during early or late pregnancy, or at delivery.<sup>46</sup>

Children of minority families are disproportionately represented among those with HIV infection. Although only 15 percent of all children in the United States are African American, and only 8 percent are Hispanic, these minorities have accounted for 51 and 26 percent, respectively, of reported AIDS cases in children.<sup>47</sup>

The following pediatric AIDS cases were reported by exposure category and race/ethnicity between April 1992 and March 1993 in the United States by the Centers for Disease Control. The total number of pediatric AIDS cases reported during this time period is 4,480. White totals were 907, African American 2,447, Hispanic 1,082, Asian/Pacific Islander 19, and American Indian/Alaska Native 15. The major form of exposure is through injecting drug use with 1,768 and the second is sex with injecting drug user with 761 cases reported.<sup>48</sup>

## Women and HIV Infection

More than 20,000 women in the United States have been diagnosed with

acquired immunodeficiency syndrome (AIDS) as of November 30, 1991 (CDC), and it is estimated that 105,000 women may currently be infected with HIV (CDC, 1990a). Although women represent a minority of AIDS cases in this country, the number of women affected is increasing rapidly, doubling every 1 to 2 years. In the United States, women represent 10 percent of all AIDS cases, and disease transmission for more than one-half of these women has been associated with injection drug use.<sup>49</sup>

Minority women are disproportionately represented. Among women with AIDS, 27 percent are white, 20 percent are Hispanic, and 52 percent are African American. A striking consequence of this overrepresentation is that the 1988 AIDS death rate among African American women ages 15 to 44 (10.3 per 100,000) was nine times the rate among same age white women (1.2 per 100,000). AIDS was the leading cause of death among African American women of reproductive age. Minority women are primarily at risk due to their and their partners' drug use.<sup>50</sup>

## Low Birth Weight (LBW)

Despite contemporary reductions in LBW morbidity compared to disability rates before the introduction of neonatal intensive care, permanent neurodevelopmental problems are seen in many survivors. Such problems include major neurosensory handicapping conditions, cognitive and language delays, specific neuromotor deficits, neurobehavioral and socioemotional abnormalities, and school dysfunction. The major neurosensory handicapping conditions associated with prematurity are cerebral palsy, particularly of the spastic diplegia type; mental retardation (i.e., intelligence quotient [IQ] more than two standard deviations below the standardized test mean); sensorineural hearing loss; and visual impairment, primarily the consequences of retinopathy of prematurity (ROP). These major developmental disabilities may occur together in the same child and occasionally are complicated by progressive hydrocephalus or a



chronic seizure disorder. They usually are clinically apparent by 2 years of age and vary in severity from mild to profound. Children with one or more of these major disabilities generally require special educational programming and individual therapeutic intervention throughout childhood. These conditions occur two to five times more frequently in LBW compared to full birth weight (FBW) infants.<sup>51</sup>

More than 250,000 low birth weight infants (LBW <2500 g) are born each year in the United States, constituting approximately 7 percent of all live births. Of these infants, approximately 50,000 annually are of very low birth weight (VLBW <1500g), constituting approximately 1.5 percent of all births. Since the estimated LBW incidence has remained relatively stable over the past 30 years, contemporary reductions in neonatal mortality are steadily increasing the prevalence of biologically vulnerable infants and children in the overall population.<sup>52</sup>

Low birth weight infants have neurodevelopmental disabilities at three times the rate of normal birth weight babies. These disabilities include long-term disabilities, such as cerebral palsy, autism, mental retardation, developmental delays, hearing impairments, and mental disorders, with risk increasing as birth weight decreases (Food Research and Action Center, 1984; Institute of Medicine, 1985; National Center for Clinical Infant Programs, 1986; E.Q. Johnson DounsRION, 1983).<sup>53</sup>

Extremely low birth weight (less than 1000 grams) is known to be a major risk factor for a variety of developmental disabilities, including school problems. About 25 percent of these babies experience serious disabilities, while another 40–65 percent present learning disabilities, hyperactivity, attention deficits, and other problems.<sup>54</sup>

## Infant Mortality

Mortality rate has long been regarded as the prime measure of the overall health status of a population. Total infant mortality is also used for comparative purposes. In 1988 (the most re-

cent year for which international data are available), the United States ranked 23rd, up from 20th in 1980 (Centers for Disease Control, 1993). Moreover, the relationship between socioeconomic status and infant mortality was first documented in the United States in 1925 (Woodbury, 1925).<sup>55</sup>

## Adolescent Childbearing

Adolescent childbearing is a major expense to society. Results from studies in 1979 and again in 1985 indicate that families headed by teenage mothers received 60 percent of the Aid to Families with Dependent Children (AFDC) budget. These studies also calculated that in 1985, \$16.5 billion in public assistance went to families in which the mother was a teenager at the time of giving birth to her first child.<sup>56</sup>

## Fetal Alcohol Syndrome

Fetal alcohol syndrome (FAS) affects approximately 1 in every 750 live births in the U.S., with higher prevalence rates among African Americans and Native Americans. Nationally, about 5,000 newborns per year display the dysmorphism associated with FAS. FAS children exhibit intrauterine and postnatal growth deficiencies, specific facial abnormalities (e.g., small head, short nose, indistinct philtrum), and possible brain and heart malformations. Associated behavioral and cognitive impairments, including mild mental retardation, are also often present.<sup>57</sup>

## Women

Women occupy a disadvantaged societal position as a consequence of traditional sex role socialization patterns (e.g., women as homemakers). Although men may be victimized by the restraints of cultural expectations, traditional socialization patterns send oppressive messages to women about power, economic independence, occupational aspirations, physical attractiveness, sexuality, and family roles. When a woman has a disability, the messages and stereotypes become even

more complex. Britt (1988) asserted that being a female and possessing a disability in society compounds the effects of stigmatization. The negative impact of the double stigma offered by Britt may be illustrated in numerous ways, but none as clearly as a cursory examination of the employment statistics for women with disabilities. For example, Bowe (1984) reported that nearly 60 percent of nondisabled women are employed as compared to less than 20 percent of women with disabilities. More disheartening is the statistic that employed women with disabilities earn only 74 percent of the income of employed nondisabled women (Thurer, 1982; Vash, 1982). Also, the income level of women with disabilities is far below the income levels for both nondisabled men and men with disabilities.<sup>58</sup>

For the African American woman with a disability, life can be further complicated by the additional stigma of being an ethnic minority. African American women are considered one of the most disadvantaged groups in America (Reid, 1984; Brown-Collins & Sussewell, 1986). Although the educational and occupational levels of African American women are higher than those of African American men, they are still considerably lower than those of white males and females (Burlew & Johnson, 1992; Gainor & Forrest, 1991). Furthermore, African American women, unlike their white counterparts, must face intra-group issues of sexism surrounding family and community interactions with African American men. Consequently, African American women are at greater risk for depression and poor self-esteem (Gray & Jones, 1987). If the observations cited above are true for the majority of African American women, it can be suggested that the presence of a disability will exacerbate the group specific difficulties of everyday functioning as an African American female.<sup>59</sup>

African American women with disabilities occupy a distinct role among rehabilitation clients. Their multiple minority status presents specific rehabilitation issues associated with gender, ethnicity, and disability. Therefore, rehabilitation professionals are faced with



a unique challenge. They can effectively manage this challenge by developing greater awareness of the psychosocial and vocational problems experienced by African American women who are disabled. In addition, they must identify and utilize counseling approaches from various human service disciplines (e.g., family studies, psychology, and social work) that address the special adjustment situations of African American women with disabilities. A sincere effort to effectively serve this client population is imperative.<sup>60</sup>

The African Americans with a disability are more likely to be female (53.9 percent), to be 42 years of age, to have less than a high school education, and to be unemployed.<sup>61</sup>

## Environmental Illness

The defining characteristic of environmental risk factors is that they are health related risks that exist outside the person and over which the individual has little or no control. There are two types: social and physical. The social-environmental risk factors overlap to some extent with the lifestyle and behavioral risk factors, but are primarily the product of societal structures. The physical-environmental risk factors are primarily the product of the built (i.e., human-made) environment.<sup>62</sup>

Environmental factors that can cause mental retardation include toxins, such as drugs and industrial chemicals, and bacterial and viral infections. Each year we synthesize over 50,000 new compounds in the U.S., many of which probably should not be ingested, inhaled, or otherwise introduced into the human body. The effects of many of these harmful agents (e.g., lead) may be lessened with enhanced maternal nutrition, which can limit but not eliminate the absorption of many toxins into the systems and organs of the fetus (Davis, 1988).<sup>63</sup>

Exposure to lead is one of the most chronic environmental pediatric health problems in the United States. Lead exposure primarily affects the central nervous system and can lead to decreases in intellectual functioning. Current es-

timates place the number of lead exposed children in the U.S. at about three million, or one of every six. However, there is certain to be underreporting of this condition, particularly among those very populations at greatest risk. Only about 7 percent of young children from medium and high income families are overexposed, while the rate jumps to 25 percent for poor white children and 55 percent for those from impoverished African American families. The problem is compounded by the fact that poor children are less likely to be evaluated for exposure through measuring concentrations in blood or teeth.<sup>64</sup>

## Stress

Stress has been described as a feeling of being under pressure, of not being able to cope, of irritability, anxiousness, and of things being out of control. Stress affects individuals in different ways; some manifestations of stress include decreased job productivity, increased absenteeism, increased worker dissatisfaction, deteriorating health, problems in interpersonal relationships, and increased use of alcohol and drugs. Many of these same factors have been associated with the onset of disability in employed people, whether due to accidents on or off the job, chronic health problems, or the sudden appearance of health problems. The combination of loss of control, emotional distress, and disability often becomes a constraint to communication and redress of difficulties for disabled workers, who, due to the stress they may be experiencing, are often unwilling or unable to seek the help of disability management resources, such as trained supervisors, employee assistance programs, or rehabilitation referrals. Moreover, cooperation of the disabled worker is necessary for active employee participation in achieving the optimum person-environment fit on the job based on individual and organizational characteristics.<sup>65</sup>

Disability status is usually a distressing personal experience. The physical, emotional, and social consequences of a disability can be so stressful that behavior is not directed toward adaptive

relearning but toward reducing the terrible stress, anxiety, and other emotional discomforts to an acceptable level, even if that behavior is maladaptive and unproductive. When this happens, less energy is available for adaptive behavior, constructive problem solving, and to improve functioning. At least three such stress-related disorders are common in rehabilitation, and they appear to be more common in the elderly.<sup>66</sup>

Dependency behavior also can be stress related. Dependency often represents an attempt to control the behaviors of others so that there is more consistency and predictability in their actions. Dependency has several elements. One is attributing causality to others; another is attempting to reduce stress by controlling the actions of others. For example, dependency may be expressed by stating or implying that the actions of other people cause the person to feel or act a certain way (usually the family).<sup>67</sup>

The evidence strongly supports the conclusion that stress can affect physical and mental processes in ways that might alter an individual's susceptibility to disease.<sup>68</sup>

As part of the research with families of chronically ill children, the researchers systematically assess the coping behaviors parents employ to successfully manage family life. This systematic assessment involved the use of a self-report questionnaire, *Coping Health Inventory for Parents* (CHIP). Using this coping inventory, three coping patterns that parents use to manage family life when a child has a chronic illness emerged; they are:

- maintaining family integration, cooperation, and an optimistic definition of the situation;
- maintaining social support, self-esteem, and psychological stability; and
- understanding the medical situation through communication with other parents and consultation with the medical staff.<sup>69</sup>

## Secondary Condition

A secondary condition is a condition that is causally related to a disabling



condition (i.e., occurs as a result of the primary disabling condition) and that can be either a pathology, an impairment, a functional limitation, or an additional disability.<sup>70</sup>

According to Marge (1988), among the most commonly reported secondary conditions are pressure sores, contractures, urinary tract infections, and depression, each of which can cause additional impairment, functional limitation, and disability. Specific examples of the relationship between a primary disabling condition and resultant secondary conditions include decubitus ulcers and contractures that develop because of lack of movement in a person with paraplegia and depression that develops as a result of spinal cord injury.<sup>71</sup>

The causal relationship of a secondary condition can be either direct or indirect. The common example of a direct etiological relationship is the development of pressure sores in people who use wheelchairs and are limited in activity as a result of spinal cord injury. An example of an indirect relationship is that of a disabling condition that causes new stresses, uncertainty about the future, changes in living environments and social relationships, and frustrations from being unable to gain access to a building that in turn can cause hypertension or other stress-related diseases. In addition, disabling conditions can magnify the influence of other existing risk factors. Continuation of smoking, heavy drinking, poor dietary habits, and other deleterious behaviors greatly increase the likelihood that a secondary condition will develop.<sup>72</sup>

## Summary

We have discussed the expanding or new universe of disability that is resulting from changing causes in the sociological, economic, medical, and biological environment and in patterns of disabilities which include but are not limited to such conditions as violence and abuse; aging; substance abuse; stress; inadequate prenatal care; low birth weight; adolescent pregnancy and childbearing; poor nutrition; secondary conditions; environmental/toxic expo-

sure such as alcohol, smoking, drug abuse, and lead; sexually transmitted diseases, including pediatric HIV and AIDS; injuries; and child abuse and neglect. The point is made that researchers need to identify and describe these populations in terms of socioeconomic, education, ethnic/cultural, geographic and other factors and by the disability related consequences, including functional loss, employment, and social behavior.

A major theme of this paper is that violent and abusive behaviors continue to be major causes of death, injury, and stress in the United States. Suicide and homicide have resulted in over 50,000 deaths annually between 1985 and 1991 and victims of violence have exceeded 2 million people annually. Violence produces extensive physical costs and emotional consequences for society. In the communities today, domestic violence, spouse abuse, child abuse, child sexual abuse, and elder abuse are the most common manifestations.

In any research agenda dealing with a changing universe of people with disability, epidemiology and surveillance play primary roles in

- accurately determining the dimensions of the populations of people with disabilities,
- identifying the causes of disabilities,
- guiding the development and selection of preventive interventions, and
- evaluating the implementation of interventions.

The research agenda suggested above should also include:


- the prevention of secondary conditions,
- the relationship between socioeconomic and psychosocial disadvantage and the disabling process,
- the environmental risk factors, both social and physical, that exist outside the person and over which the individual has little or no control,
- the prevalence of specific types of disabilities among ethnic minorities,
- the violence and abuse against women with disabilities, and
- the people with longstanding disabilities who are growing old and older people who are becoming disabled.

Of the many emerging issues cited within this paper, five are central themes throughout:

- There must be continued expansion of research into these emerging issues.
- Ongoing research within the medical, engineering, social, and targeted populations needs to be continued.
- There must be continued expansion of rehabilitation services to all people in need of them, including those who are disabled and those who are disadvantaged.
- Changes in the population requiring special education, service delivery, vocational education, or community integration should reflect the changing trends.
- There must be continuing stress on increased consumer participation and involvement in all rehabilitation programs at all levels of operation.

Thus, these and many other possible developments lie in the future of the disability and rehabilitation research program and will influence its next 75 years. Some prospects for the program seem rather clear. For example, in such an evolving picture, the federal, state, local, higher education, private sector, and the international program of rehabilitation research will be in the center of new growth patterns, with rising responsibilities for providing management expertise and coordinating mechanisms to support the total effort for people with disabilities.

The program in the future will be pursuing some intangible goals, some challenges of the mind. It will be searching—as it has for 75 years—for a better understanding of people with disabilities, for better opportunities in life for them, and for a broad social attitude in which disability never obscures ability.

To make this happen in the years ahead will require forging new partnerships, adopting new styles, using new technology, taking new risks, and employing all of the knowledge, the spirit, and the positive momentum of the past. There is no challenge more worthwhile and no work more fundamental to our national purpose. 



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### Recent Poll Shows Strong Business Endorsement of ADA

Almost three-fourths (73 percent) of the top industries across the United States are currently hiring people with disabilities, according to a recent survey. Although some have attacked the value of legislation such as the Americans with Disabilities Act (ADA), 54 percent of people who make hiring decisions for these companies claim that ADA has had a positive impact on corporations. Only 16 percent believe ADA has had a negative effect.

Conducted from October 17 to 31, 1995, by Global Strategy Group, Inc., a New York based polling firm, for the President's Committee on Employment of People with Disabilities, the survey consisted of a nationwide random sample of 300 CEO's and Human Resource Managers in Fortune 5000 companies related to manufacturing, technology, and communications and carries a margin of error of plus or minus 5.7 percent.

Looking at the data by industry, 66 percent of executives in the field of technology believe ADA has had a positive impact as do 52 percent in the communications industry. Slightly less than half (46 percent) of all manufacturing human resource managers think ADA has made a positive impact on companies across the United States. Regionally, 59 percent of those in the East and 51 percent in the South find ADA to have made a positive impact while 47 percent in the Midwest/West say the same.

Technology-based industries are not only the most likely to extol the virtues of ADA, but also demonstrate the most impressive record of hiring people with disabilities (76 percent), although the manufacturing industry is not far behind (74 percent). And while the communications industry personnel are the least likely to be hiring people with disabilities, their record is still an impressive 69 percent.

Hiring people with disabilities appears to correlate more with the size of companies. An inspiring 87 percent of companies with more than 200 employees are hiring people with disabilities as are 75 percent of companies employing 51-200 people. More than half (58 percent) of companies with less than 50 people are hiring people with disabilities.

#### The survey revealed several other major findings:

- A majority (51 percent) of these companies are looking for access to qualified applicants so they can move forward with hiring individuals with disabilities. Another 16 percent would like job accommodation information, while 9 percent need awareness training and a similar number need more information on ADA.
- The government (22 percent) and the media (20 percent) are the best sources for information on ADA. Slightly less than one in five (18 percent) use their lawyer for information while 12 percent attend seminars.

A July 1995 Louis Harris and Associates, Inc., survey, conducted for the National Organization on Disability (1995 NOD/Harris Survey on Employment of People With Disabilities), showed that a large majority (70 percent) of senior corporate executives support ADA and another 8 percent believe it should be strengthened; in the same poll, 89 percent of employers supported policies to increase the number of people with disabilities in their companies. A January 1995 poll conducted by Mason-Dixon and funded by the Florida Chamber of Commerce Foundation's Disability Awareness Project showed that, on the basis of the experience of chamber members, 87 percent of employers who had hired persons with disabilities would encourage other businesses to do likewise.



# Challenge and Progress in Rehabilitation

## A Review of the Past 25 Years and a Preview of the Future

*Empowerment of individuals with disabilities, the emergence of models for community living, adaption of services for minority groups, and increased services to older persons are examples of dramatic changes that have transpired in rehabilitation during the past 25 years. By reviewing these changes, as well as the shift in the philosophical base supporting rehabilitation, previous forecasts about rehabilitation's direction are reconsidered; and predictions are made about the course of rehabilitation during the final quarter of its first century.*

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The field of rehabilitation has changed significantly during the 25 years since its 50th anniversary in 1970. At that time, Thomas (1970) divided the history of rehabilitation into periods that were synchronized to landmark government initiatives. Joining Thomas by writing in the same anniversary issue of *Rehabilitation Record* (the journalistic precursor of *American Rehabilitation*), other influential persons in the field presented their views about the preceding half century of rehabilitation. The convictions that progress had resulted from government initiatives and from the activities of extraordinary professionals were common themes uniting their views.

Writing 1 year earlier, DiMichael, Garrett, and Switzer (1969) noted vital momentum as the identifying characteristic of American vocational rehabilitation. This momentum explained the remark-

able, sustained advances in rehabilitation as a result of a movement that "refuses to slow down and live on its past" (Maliken & Rusalem, 1969, p. 3). Maliken and Rusalem (1969) predicted changes in rehabilitation, giving as examples alternative residence programs, techniques for helping nonmotivated clients, and community-based services. Reports from committees and conferences during the late sixties and early seventies emphasized the need to expand both public and private rehabilitation and to decentralize federal services (Rehabilitation Services Administration, 1970). Carney (1990a), reviewing 70 years of progress in state and federal vocational rehabilitation programs, noted three principles that had prevailed among programs during this period: systemization, individualization, and flexibility. She predicted that these principles would continue to prevail in subsequent eras.

Once viewed by some as an extension of government agencies, rehabilitation has become less agency domi-

nated and more individual client centered. Although still linked to legislation and government funding, rehabilitation has emerged from the shadow of government patronage and developed an independent identity (Boggs, Hanley-Maxwell, Lakin, & Bradley, 1988; Halloran, 1993; Laski, 1985). In many ways, legislation has been transformed from the primary cause of social change into a response to change. Williams (1987) summarized a view of many when he observed that a "shift from leadership by rehabilitation professionals to leadership by disability activists has taken place over the past twenty years . . ." (p. 59). The clarity of this view is even more apparent today than it was 8 years ago.

Examples of areas where dramatic changes have taken place include employment, technology, models for living, rehabilitation of individuals with severe disabilities, and delivery of services to special populations, such as older persons and minority groups. However, there is no change more dramatic than that in the philosophy supporting rehabilitation. This shift has resulted from an acknowledgment that disability is a natural part of the human experience (Rehabilitation Act Amendments of 1992, PL 102-569). Not only professionals are involved with rehabilitation, but a good portion of the general public now recognizes that people with disabilities have the right to live in their communities, to interact with individuals in the broad mainstream of society, to be employed in

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meaningful jobs, to be independent, to make choices about daily living, and to participate in decisions about the services they receive. Wright's 1980 holistic definition of rehabilitation, "... helping a handicapped individual [sic] live rewardingly" (p. 4), would be accepted by even more people today than those that accepted it 15 years ago.

Boggs (1994) reviewed legislative benchmarks and political events foreshadowing recent changes. On the basis of this review she conceded that it was difficult to mark "... any one moment in time as birth of a new ideal or paradigm, given the inevitable overlapping of ideas and movements..." (p. 54). Despite the risks of identifying historical milestones that divide a continuum of activity into segments, occurrences during the past 25 years have had an irreversible impact on rehabilitation. By itself, this impact would warrant a review of events from the period. But there may be another advantage in such an historical analysis: a review of the field during the past 25 years may provide clues about the course rehabilitation will take during the next 25 years.

## Legislation

Maliken and Rusalem (1969) identified the Vocational Rehabilitation Act of 1920 as the single most important piece of legislation of the first 50 years of rehabilitation in the United States. They were struck that a piece of legislation, with its amendments, could retain its "dynamic potential" for so long. Although rehabilitation is not tied to legislation to the degree that it once was, there have been several pieces of legislation during the past 25 years that have had the potential to change the lives of all individuals with disabilities. The most notable of these was the Americans with Disabilities Act of 1992 (ADA), which may rival the longevity of the Vocational Rehabilitation Act of 1920.

ADA established enforceable standards to redress discrimination against individuals with disabilities. The act was intended primarily to protect the civil rights of all people with disabilities (Carney, 1990b). Disability was defined

as physical or mental impairments, or the perception that one had such impairments, to extents that substantially limited major life activities. ADA was designed to include everyone who would qualify for rehabilitation. In addition to individuals who traditionally qualify for rehabilitative services, persons who are infected with HIV are protected. The major life activities identified by ADA go far beyond the vocational domain and include habilitation tasks such as self-care, mobility, communication, and learning.

With regard to employment, ADA provides safeguards against non-equitable salaries and unfair discharges from jobs. But it also details protection in such areas as job application, hiring, advancement, training, and qualification for employment benefits. It specifies reasonable accommodations that employers should provide at their own expense in order to ensure occupational opportunities for individuals with disabilities. Although the provisions of

***Changes in living arrangements may provide the most convincing evidence for the growing independence of persons with disabilities.***

ADA parallel many of those in the Rehabilitation Act of 1973 and its amendments, the Rehabilitation Act of 1973 applied only to employees of businesses receiving federal assistance. ADA applies to all individuals with disabilities and is mitigated only in cases where accommodations create undue hardships.

The most recent amendments to the Rehabilitation Act of 1973, approved during 1992 (PL 102-569), underscore that vocational rehabilitation extends to individuals with the most severe disabilities. The amendments also high-

light the rights of individuals receiving services to participate in the planning of the programs affecting them, the need for assistive teams involving a cross section of professionals, the development of programs that rely on interagency and extra agency cooperation, and the priority of services to individuals from minority groups.

## Independence Through Community Living

Changes in living arrangements may provide the most convincing evidence for the growing independence of persons with disabilities. For example, there has been a major shift from institutional to community living during the past 30 years. Hayden and Abery (1994) indicated that more than 100 residential institutions have closed during the past 35 years. The number of people living in institutions has decreased by more than 120,000 during this 35-year period. Conversely, the number of people with disabilities living in community settings has increased by almost 200,000 during the past 15 years alone. Attrition from institutions has taken place in response to debate about whether public institutions or community living facilities offer a higher quality of life for individuals with disabilities (Nosek, 1992; Stumpf, 1990) and because of increased funding for community-based residential placements from state governments (Brad-dock & Mitchell, 1992).





The goal of these residential placements is to help people with disabilities make decisions, become employed, maintain careers, establish personal relationships, and preserve access to their communities. Though there are multiple models of community living, the precise formula for recommending optimal models for specific clients is uncertain. Nonetheless, there is a widespread and growing conviction, indicated by data about changing patterns in living arrangements, that people with disabilities and their families must participate in all decisions about their residence (Giordano & D'Alonzo, 1994).

## Independence through Technology

Technology is another force that has increased the independence of people with disabilities. Assistive devices have been designed to improve mobility, communications, health maintenance, cognition, vision, social activities, recreational activities, and daily living (Chandler, Czerlinsky, & Wehman, 1993). Although the organized field of assistive technology and the computerized devices that are employed within it are relatively new, many of the concepts in this field have been incorporated within rehabilitation by professionals for decades (Chandler, Czerlinsky, & Wehman, 1993; Sowers & Powers, 1991;

Wehman, Wood, Everson, Goodwyn, & Conley, 1987). Bowe and Deal (1984), making predictions about rehabilitation technology that will be in effect at the turn of this century, were convinced that advances in computerized communication, assisted listening, and text recognition equipment would eliminate the need for many of the special rehabilitative accommodations that were being employed in the early eighties. Already, adaptive devices for persons who are visually impaired have significantly increased their opportunities to learn, to be employed, and to interact with people in their communities (Ryder, 1992).

Support for assistive technology was provided by the 1986 Amendments (PL 99-506) and 1992 Amendments (PL 102-569) to the Rehabilitation Act as well as the Technology-Related Assistance for Individuals with Disabilities Act (PL 100-407) of 1988. Additional funding for assistive technology had become available through Social Security, Medicaid, Medicare, and several pieces of legislation, including the Education for All Handicapped Children Act of 1975 (PL 94-142) and its subsequent amendments. ADA did not provide funding for technology and environmental adaptations, but it did ensure that public and private employers would promote and fund accessibility, which could entail technology and environmental adaptations.

Another impetus behind these technological advances has been the opportunity for private sector entrepreneurs to make profits through cost effective services (Parette & Van Biervliet, 1990; Welch, 1984). Cost effectiveness, which restricts the accessibility of assistive technology, became a priority issue during the development of assistive listening devices ("Assistive Listening Devices," 1990), augmentative and alternative communication devices ("Augmentative and Alternative Communication," 1993), telecommunications for individuals with disabilities ("Telephone Services," 1987), robotics devices ("Robotics and Rehabilitation," 1987), assisted driving equipment (D'Alonzo & Giordano, 1993), and a broad menu of assistive

technical aids ("Assistive Technology," 1993; "Assistive Technology Services," 1993). Morissey and Silverstein (1989) characterized the Technology Act of 1988 as a response to "... the belief that, although federal funds are limited, such funds can serve as a catalyst to redirect other funding to the technology needs of people with disabilities" (p. 28). Lazzaro (1993) listed primarily private businesses when he identified influential organizations that were providing assistive technology to persons with disabilities.

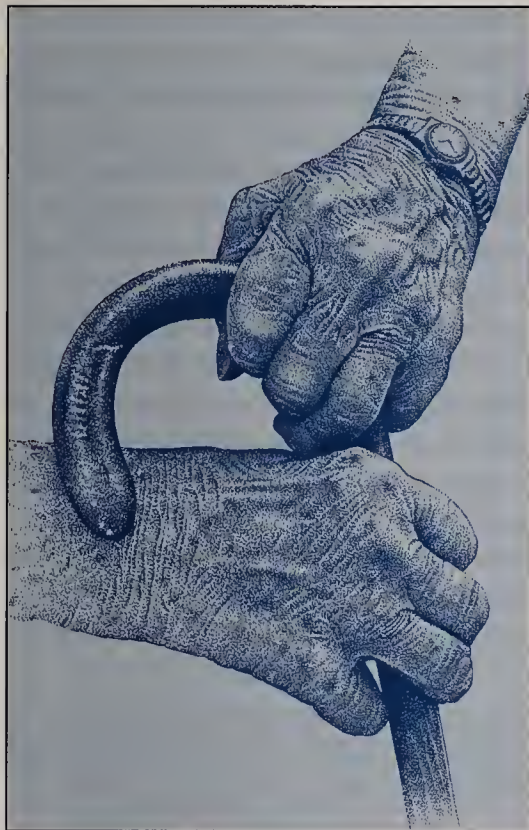
## Rehabilitation for Minority Groups

People from minority groups have had disproportionately high rates of disability and unemployment (Meyerson & Weddington, 1986; O'Connell, 1987). Examples of disabling conditions that have occurred with unusual frequency among the members of some minority groups include alcoholism, mental health problems, communication disorders, and drug abuse ("Cross Culture Rehabilitation," 1988; D'Alonzo, Giordano, & Oyenque, in press; "Indigenous Americans," 1991; "Rehabilitation of Nonwhite," 1987; Stewart, Anae, & Gipe, 1989).

Traditionally organized rehabilitation programs have been largely unsuccessful with individuals from minority groups. Because of the incongruity between the assumptions of such rehabilitation programs and the values on which minority group cultures are based, sensitivity to clients' cultures, backgrounds, and beliefs have been cited repeatedly in the professional literature as indispensable conditions for effective rehabilitation among minority populations (Atkins, 1988; Chan, Lam, Wong, Leung, & Fang, 1988; Cheng, 1989; Cuellar & Arnold, 1988; "Culturally Sensitive," 1993; D'Alonzo, Giordano, & Oyenque, in press; De la Rosa, 1989; Kuehn and Imm-Thomas, 1993; Kuncie & Vales, 1984; Martin, Frank, Minkler, & Johnson, 1988; McCormack, 1987; Medina, Marshall, & Fried, 1988; Morgan, Guy, Lee, & Cellini, 1986; Morgan & O'Connell,

***People from minority groups have had disproportionately high rates of disability and unemployment.***





1985; Pedersen, Draguns, Lonner, & Trimble 1989; Rogler, Malady, Constantino, & Blumenthal, 1987; Toubbeh, 1989; Zuniga, 1992).

## Rehabilitation for Older Persons

Older persons constitute more than 12 percent of the population in most western countries. As a result of increasingly sophisticated healthcare and social services, this percentage should double over the next 25 years (Lazlett, 1991). Although longevity occurs less often among persons with disabilities, their prospects for achieving old age and living longer are increasing (Sutton, Factor, Hawkins, Heller, & Seltzer, 1993). Physical and psychological factors that are difficult and sometimes impossible to change may influence the longevity of individuals with disabilities. However, circumstantial factors that can be changed are often involved as well. Examples of modifiable circumstantial factors include finances, interpersonal support, specialized expertise of healthcare professionals, availability of role models, and community support services (Trieschmann, 1987).

Hawkins (1993), researching the degree to which older persons with disabilities were satisfied with themselves and their lives, noted a correlation between active life styles and self-satisfaction. She concluded that older persons with disabilities benefited not only physically but cognitively and emotionally when they participated in programs that encouraged recreation, leisure, and community activities. Although employment can be a critical component of the active lifestyle that benefits older persons with disabilities, the probability of employment decreases as age increases ("Aging With," 1988). Factor (1993) reviewed programs that had attempted to meet the late-life needs of individuals with disabilities through employment or through retirement with continued meaningful activities in the community.

## Personnel Needs

Writing in 1950, Hamilton noted that though personnel support for individuals with disabilities had increased in some areas, there was a shortage of rehabilitation counselors. Twenty years later, Newman (1970) reported a shortage of personnel in rehabilitation that was serious and likely to persist. As a response to the shortage, he recommended that qualified personnel be trained in community colleges as well as in universities. He also proposed that nonprofessionals be trained to support rehabilitation programs in areas where there were not adequate resources. Examples of responsibilities that could be discharged by nonprofessional personnel could be those of attendants to persons with disabilities ("Attendant Services," 1988), job coaches (Gilbride, 1993), and assistants to vocational rehabilitation counselors (D'Alonzo, Giordano, & Oyenque, in press). Additional pressure to develop nontraditional training and certification programs has come recently from practitioners in private sector rehabilitation who have noted the shortage of appropriately prepared personnel (Field, 1993).

Although the shortage in rehabilitation counselors during the seventies had leveled off by the end of that decade, Wright (1980) predicted continued shortages of personnel trained to aid individuals who were from cultural minorities, who required support for independent living, or who exhibited special medical problems. Recent surveys of employment opportunities in rehabilitation have underscored the need for both rehabilitation counselors as well as specially trained personnel ("Careers in Rehabilitation," 1992; Cohen & Pelavin, 1992).

McFarlane (1992) identified specialized careers in rehabilitation such as psychology, prosthetics, physical therapy, occupational therapy, speech-language pathology, audiology, technology, counseling, mobility, occupational evaluation, administration, interpreting, health, and medicine. Plentiful personnel opportunities in these specialized areas should continue to occur within public rehabilitation programs and educational programs as well as within business, industry, and private practices (Matkin, 1995).

A 1987 report recommended that training for careers in rehabilitation be altered so that professionals would be better prepared to participate in interdisciplinary teams and that they "... direct more of their time and energies to the employment environment" (Williams, 1987, p. 59). Persons working in for-profit rehabilitation businesses may require a different emphasis in training from that which is appropriate for persons employed in public sector programs. Market sensitive skills in areas such as consultation, expert testimony, disability management, ethics, and legal issues have been suggested as topics for such a differentiated curriculum (Crystal, 1993; Gilbride, 1993).

## Private Sector Rehabilitation

Wright (1980) noted that rehabilitation services were available through three types of organizations: public agencies, private nonprofit associations, and private profit making businesses.



In eight chapters of his comprehensive textbook, he elaborated about public agencies and private nonprofit associations. However, his accounts of private profit making businesses were minimal.

Carney (1992) reviewed 19 years of activity under Projects With Industries (PWI), a program intended to promote the participation of private businesses in rehabilitation. PWI placed more than 13,000 people with disabilities into competitive employment in 1991. Carney cited the supported employment initiatives of the 1980's as other examples of programs built on cooperation between the Federal Government and private businesses. She credited these initiatives with more than 50,000 placements of individuals with severe disabilities in integrated employment settings during 1991 alone.

During the past 15 years, there has been a dramatic increase in the private sector's involvement in rehabilitation technology, residential care, speech-language pathology, audiology, occupational therapy, physical therapy, health, and medicine. A 1985 survey estimated that there were 8,000 practitioners employed at 1,500 private rehabilitation companies ("Vocational Rehabilitation," 1985). There are currently more rehabilitation practitioners employed in the private arena than in the public sector (Matkin, 1995). As evidence of this transition, Field (1993) reported that the membership of the National Rehabilitation Association, which comprised persons affiliated with state agencies, declined from 38,000 members in 1973 to 17,000 in 1993. Collignon, Barker, and Vencill (1992) conducted a survey of 300 private rehabilitation firms. The responding firms accounted for one-half of the clients that were receiving private sector rehabilitation. The recent involvement of these firms was indicated by the fact that only 22 percent had been initiated prior to 1980.

There are differences in the clients served through private businesses and public rehabilitation. As an example, in the Collignon, Barker, and Vencill survey (1992), 7 percent of the clients from private firms had mental disabilities while this figure approached 50

percent for public programs. While noting that similarities were greater than differences between public sector and private sector rehabilitation, Matkin (1995) pointed out "transitory differences" such as caseload size, case recording procedures, administration, and patterns of personnel hiring. Other differences included criteria for client eligibility, types of services provided, sources of funding for services, and the goals set for rehabilitating individuals. With regard to goals, Crystal (1993) noted that a primary goal of private sector rehabilitation, which is based on the principle of compensation for lost value, is to return clients to their prior

levels of physical, mental, and vocational functioning. In contrast, the goal of public sector rehabilitation is to enable clients to achieve suitable outcomes, which are not linked to previous abilities or employment and which may be restricted by the resources available to the rehabilitation agency.

Case management and the other systems of managed care that are employed frequently by private practitioners can be cost-effective alternatives to public programs (Clifton, 1995; Field, 1993; Leone, 1995; Owens, 1993). Case management designates professional planners who can negotiate with insurance companies and rehabilitation firms to

**Table 1**  
**Predicted Developments in Rehabilitation During the Next 25 Years.**

1. Community based rehabilitation services will increase.
2. Supported employment programs will increase.
3. Individuals with disabilities will assume greater control of the programs that affect them.
4. Models of culturally sensitive rehabilitation counseling will emerge.
5. Private sector businesses will become increasingly involved in rehabilitation.
6. Tolerance and acceptance of disabilities will expand among persons without disabilities.
7. Rehabilitation technology will have an increased impact on persons with disabilities.
8. Services for older persons with disabilities will expand.
9. Programs built on partnerships between agencies, communities, and businesses will expand.
10. Life-span approaches will permeate rehabilitation.
11. Rehabilitation services will become less agency focused and more client centered.
12. Models for developing rehabilitation personnel through nontraditional programs will emerge.
13. Services for persons with severe disabilities will expand.
14. Independent living opportunities will broaden for persons with disabilities.
15. Federal and state regulations, and the implementation of those regulations, will be directed increasingly to local levels.




ensure that clients receive appropriate services at controlled costs. Should the healthcare system be reformed to increase the number of persons eligible for rehabilitative services, the differences between private and public rehabilitation firms are likely to decrease (Lui, 1993). At the same time that there is an expanding number of clients who are eligible for rehabilitation, the costs of rehabilitation are rising rapidly (Clifton, 1995). Field (1993) predicted that these two issues would cause dramatic changes in both state agencies and private insurance companies.

There have been three influential pieces of legislation that have expanded the markets for private rehabilitation firms. These are the Americans with Disabilities Act, the Individuals with Disabilities Education Act, and the 1992 reauthorization of the Rehabilitation Act. All three emphasized common themes that could be linked to the interests of private sector rehabilitation firms, such as independent living, community based services, the right to work, the need for accessibility, quality of life, and maximum independence (Chubon, 1995). As an example of a private sector response to these themes, employment firms have emerged that evaluate individuals with disabilities, train them, place them in jobs, and then support them after employment (Lui, 1992). Gilbride (1993) indicated that not only were rehabilitation professionals employed as rehabilitation specialists in private for-profit practices but they were employed frequently as personnel directors, ADA consultants, transdisciplinary team members in medical and psychiatric settings, insurance company consultants, career advisors, and substance abuse counselors.

On the basis of opportunities created by legislation, emerging models of disability management within insurance companies (Owens, 1993), and the successful record of private sector rehabilitation, one can predict an increased involvement of private business in rehabilitation during the next 25 years (Table 1). Other predictions—which are also foreshadowed by events that have

already occurred—are included in this table as well.

## Conclusion

Progress in rehabilitation during the past 25 years has been tied to important legislation such as the Rehabilitation Act of 1973 and the Americans with Disabilities Act. But there have been significant changes which are not linked directly to legislation, such as shifting attitudes by clients, professionals, and the general public. These shifts are reflected in the increasing number of individuals with disabilities who are living in their communities. This significant development, as well as the customization of rehabilitation services to better meet the needs of older persons and individuals from minorities, is a trend that will persist. Other trends that are likely to emerge, endure, or expand and their impact on personnel needs in the field were highlighted. 

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# Rehabilitating Persons Who are Blind: 75 Years of Progress

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Since June 2, 1920, when the first Rehabilitation Act was signed into law by President Wilson—almost a full year after the bill on which it was based had first been introduced in the Senate—America has come a long way in improving rehabilitation services for individuals who are blind. Much has been written (e.g., Koestler, 1976; Lowenfeld, 1975; Obermann, 1965; Parker & Szymanski, 1992) regarding the legislative history of services to blind people since the initiation of the state-federal rehabilitation program in the United States. Few persons who were blind benefited from the original Vocational Rehabilitation Act that became law in 1920. This was due to a number of factors, including the lack of imagination on the part of the Vocational Education Boards, which considered blindness to be so severe a disability as to constitute a hopeless impediment to employment. It was also due in part to the limitations of the legislation itself, which made no provision for medical intervention that might remove and/or ameliorate the condition of blindness (Koestler, 1976).

The Vocational Rehabilitation Act of 1920, as finally approved, followed the pattern of earlier legislation for vocational education in setting standards to be met by the states in order to qualify for federal funds. Under this early legislation, rehabilitation services for individuals who were blind varied widely in quality from state to state, uniform only in their failure to adequately meet the needs of clients who were blind or severely visually impaired (Tenbroek & Matson, 1959). The initial vocational rehabilitation legislation, which was

also known as the Smith-Fess Act (PL 66-236), was administered by the Federal Board of Vocational Education and authorized a variety of services, including vocational guidance, occupational adjustment, and placement services for civilians with physical disabilities, but provided limited or no services to individuals who were blind or severely visually impaired.

In the years between 1920 and 1943, the Vocational Rehabilitation Act was amended three times, but without major changes in the law. However, there were two other major pieces of legislation which did have a significant impact on individuals who were blind. The Randolph-Sheppard Act of 1936 (PL 74-732) enabled individuals classified as legally blind to operate vending facilities on federal property. Two years later, the Wagner-O'Day Act (PL 75-739) made it mandatory for the Federal Government to purchase designated products from workshops for persons who were blind. While the Randolph-Sheppard Act and the Wagner-O'Day Act of 1938 provided employment opportunities for individuals who were blind, significant services were not provided to blind persons until the passage of the Vocational Rehabilitation Act Amendments of 1943 (the Barden-LaFollette Act). Passed during the middle of World War II, the Barden-LaFollette Act provided the first federal/state rehabilitation support for blind people. Thousands of operations were successfully performed with funds made available under the Barden-LaFollette Act, while thousands of other people who did not need surgery were fitted with low-vision aids that helped them overcome their visual limitations (Koestler, 1976).

The nation's interest in the rehabilitation and employment of persons who

are blind increased dramatically because of the number who were blinded while serving their country in the military. The Veterans Administration established rehabilitation programs at Valley Forge, Pennsylvania, and later in Hines, Illinois, where Richard Hoover developed and systematized the use of the long cane as a travel device. This set the stage for the development of orientation and mobility instruction programs and the development of the profession. For a comprehensive overview of timelines associated with various legislative issues affecting the blind community, see "Education of the Visually Handicapped: A Selective Timeline" (Scholl, 1986).

## Training of Agency Personnel

The Vocational Rehabilitation Act Amendments of 1954 (PL 83-565) provided funding to colleges and universities for the training and preparation of rehabilitation professionals, funding for the expansion of rehabilitation facilities, funding for improvement of state agencies, and authorized a variety of research and demonstration programs. At that time, there were no formal long-term training programs in place. Today, there are some 19 projects funded by the Rehabilitation Services Administration (RSA) under the Rehabilitation of the Blind discipline at a level of about \$1.9 million (RSA, 1995). These training programs include both

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undergraduate and graduate training in orientation and mobility, rehabilitation teaching, rehabilitation counseling, and specialized training programs in access technology and low vision. RSA also currently funds two braille training projects under Title VIII at a total of approximately \$400,000. The Office of Special Education Programs (OSEP) likewise provides long-term training grants for university-based personnel preparation programs.

## Service Delivery Changes

The literature does not reflect how many people who were blind were rehabilitated during the period 1920 through 1925; however, records are available which indicate that the number of rehabilitants was extremely small during the early years of the VR program. For example, Tenbroek and Matson (1959) indicate that state officials were often hampered by jurisdictional disputes among state offices of labor, public welfare, and vocational education as to which agency should control the program, and rehabilitation officials tended, for the most part, to shirk or minimize the arduous task of training and finding employment for those who were blind. These authors report that in the years 1935–1943 inclusive, a total of only 1,779 “sightless clients” were rehabilitated into vocations by the state agencies—or about four and one-half persons per state per year. Data reported by Lesowitz (1970) in a statistical history of the state-federal program of vocational rehabilitation (VR) for the period 1920–1969 reflect that some 399 people who had a major disabling condition of blindness or other visual impairment were rehabilitated in 1925 while 18,218 were rehabilitated in 1968. (See Table 1 page 26)

Since that time, the number of people rehabilitated who were blind or severely visually impaired has not gone up dramatically, even though the prevalence and incidence rate of blindness has increased. For example, unpublished data from the RSA *Case Service Report* (RSA-R-911) for FY 1994 reflect a total of 19,095 blind or visually im-

paired people who were rehabilitated during FY 1994. These are people whose major disabling condition was recorded as blindness or another severe visual impairment, with 11,085 people reported as being blind and 8,010 reported as “other visually impaired.” Several agencies did not submit Case Service Reports (R-300’s and R-911’s) to RSA during the period 1969 to 1994. The data reported in Table 1 are generally considered to be an underrepresentation of the actual number of blind persons rehabilitated during that timeframe (personal communication from Larry Mars, March 17, 1995).

## Organizational Structure

Persons who are blind or severely visually impaired obviously have many needs other than vocational or occupational. Many states recognized the need for state commissions for the blind to help administer programs designed to meet their special social, medical, psychological, and economic needs. A number of states established separate commissions for the blind prior to the original 1920 Vocational Rehabilitation Act, and by 1965, there were 36 states that had commissions for the blind (Obermann, 1965). In 1995, there were 25 separate agencies for the blind which operated under separate state plans for the blind. Many of these agencies are headed by directors who are blind. In a review of several studies regarding service delivery systems in the rehabilitation of the blind and partially sighted, Hopkins (1991) concluded that specialization is a necessary requisite to meaningful VR services for people who are blind or visually impaired. He concluded that VR services for persons who are blind or visually impaired are more efficiently and effectively organized in a separate and identifiable governmental unit, whether a division of a larger agency or as a separate agency all together.

## Access Technology

Looking back to 1920, the advances in access technology have been incred-

ible. In the 1930’s, the Library of Congress Library Program for the Blind distributed record players and provided books and magazines on phonograph records. In the 1970’s, the program expanded to include four-track tape cassette machines and books on tape cassettes. Over this same period, regular magnifiers for individuals with low vision have gradually improved; electronic magnifiers now provide access to written materials. Electronic access devices are now commonly used to allow people who are blind or severely visually impaired to access information using enhanced or compensatory sensory input. These aids include electronic travel aids, which are often used to complement travel with canes or guide dogs. In this age of computers, electronic reading aids, voice recognition input systems, and computerized access devices—such as speech output, paperless braille systems, and magnification—individuals who are blind or visually impaired are able to read and write independently in educational programs and in work settings. Thanks to these new technologies, individuals who are blind or visually impaired can generate and manipulate information by tactile or auditory means or by use of residual vision and/or large display.

Current data from the U.S. Department of Health and Human Services indicate that approximately 1 person in 20 has significantly impaired vision which cannot be further improved with corrective lenses. This figure translates into approximately 12 million Americans with visual impairments. Access to information and technology is a great leveler for individuals who are blind or visually impaired, allowing them to fully participate in our society. Alternatively, lack of such access creates a technology underclass who will be functionally illiterate in the information explosion (Wolffe, et al., 1994). Graphical User Interface (GUI) technology coupled with an accelerated and pervasive trend for displaying information in a highly visual format has hampered access to data for people who are blind. Concerns relate to personal work stations as well as to public



access information systems. Access concerns include, but are not limited to, personal computers and computer networks running on GUI access software; touch key and touch screens on microwave ovens, stovetops, video recorders, small and large electrical ap-

pliances; automatic teller machines; service and information kiosks; building directories, etc. Access technology has dramatically changed the employment outlook and the scope of employment opportunities available to persons who are blind.



*A secretary who is blind working in a modern office in the late 1930s using a "stenographic" braille writer. (Photo furnished by the American Printing House for the Blind, Inc.)*



*A totally blind individual at work using a computer with synthetic speech, a braille embosser and a talking braille writer. (Photo furnished by the Rehabilitation Research and Training Center on Blindness and Low Vision, Mississippi State University.)*

A major problem with the increased use of Graphical User Interface type programs is that individuals who are blind or have a severe visual impairment do not have access to the information presented on screen. To date, there is an increased recognition by those who manufacture and market computer programs and technology that these graphical programs as well as the new computer technologies should be fully accessible and usable by everyone. Because screen access technology which has worked for character-based information displays like a Disk Operating System (DOS) is unable to read graphics, new screen access programs and devices will soon be available to make graphical programs accessible. Persons who are visually impaired will have to acquire and learn how to use this new technology. In the years ahead, access technology will continue to have a tremendous impact in creating employment opportunities for individuals who are blind.

## Independent Living Services

The Rehabilitation Act Amendments of 1978 (PL 95-602) expanded the quality and scope of reader services for individuals who are blind and established independent living services as part of a state-federal rehabilitation program, including independent living services for older individuals who are blind. While Congress passed and the President signed this legislation into law, funding was not made available for independent living services under Title VII, Part C, until 1986. The Rehabilitation Act Amendments of 1992 (PL 102-569) amended Title VII and replaced Part C with Chapter 2 (Independent Living Services for Older Individuals who are Blind). While approximately half of the states originally received older blind independent living grants, all states now receive these grants in providing independent living services to individuals 55 or older who are blind and for whom employment is unlikely. Most state independent living programs are serving be-



tween 350 and 600 older blind clients per year (Moore & Stephens, 1994).

## Supported Employment Services

Since the passage of the original Vocational Rehabilitation Act in 1920, the primary thrust of the state-federal service delivery system has focused on employment in the competitive labor market. While Title I of the Act provided services to those who had employment potential and Title VII provides services to those who need help living more independently in their homes and communities, there was no mechanism until 1986 to provide services to those who needed ongoing support services. The Rehabilitation Act Amendments of 1986 changed that and offered something new and different for those with severe multiple disabilities. The Rehabilitation Act Amendments of 1986 (PL 99-506) authorized support to any blind individual who has not worked or has worked only intermittently in competitive employment, has been determined on the basis of an evaluation of rehabilitation potential to meet the eligibility criteria for the state VR services program, and has a need for ongoing support services in order to perform competitive work.

Supported employment was originally conceived as a mechanism to effect the transition of clients with severe developmental disabilities into work, but is now widely available to people throughout the country who are blind and/or multiply disabled. All state rehabilitation agencies now offer supported employment services as a part of their state plan and routinely place individuals who are blind with major secondary disabilities (e.g., blind and severely retarded, deaf-blind, etc.). The supported employment program is based on a model that is generally characterized as a *place-train* model. In this model, the client is placed in a competitive employment setting and then learns work skills in that setting, as opposed to the *train-place* model of traditional vocational rehabilitation—in which clients are trained for competi-

tive employment before being placed in the competitive labor market. These services are now generally available throughout the country in every state and community.

## Employment Opportunities

Today, more than ever, work is an activity of central importance in the lives of millions of Americans. Holding a job provides the means to support oneself and family, to engage in a regular, predictable daily routine, and to experience job satisfaction and increased self-esteem. People who are blind or visually impaired are no different from sighted persons in terms of the value they ascribe to being contributing members of society (Salomone & Paige, 1984). No one single piece of legislation has had as much impact on creating employment opportunities as the Rehabilitation Act. The number of veterans who were blinded during World War I and World War II had a significant impact on the state-federal VR program. During World War I, there was some employment of blind workers in industry and efforts were made after the war to place blinded veterans in factories. However, success was limited and the depression put an end to those attempts (Lowenfeld, 1975).

Employment opportunities for individuals who were blind in the early 1920's were very limited indeed. Clunk (1922) noted how public opinion relegated those who were blind to a few occupations. He noted that "regardless of a man's previous occupation, when sight was destroyed, he must either be a broom or basket maker, a rug weaver or a chair caner. A few of the higher grade men were selected for piano tuning and the very rare exceptions for professional musical work." Authors during those early years (e.g., Baker and Clunk, 1931; Barbre, 1939; Clunk, 1948; and Dresden, 1927) all emphasized the importance of employment as a fundamental requisite to an individual's happiness. In his book, *Blindness—What it is, What it Does, and How to Live with It*, Father Carroll (1961) emphasized the importance of work to the individual who becomes blind as

well as to the individual who may suffer from congenital blindness. His text had a significant impact on service delivery programs which were designed to serve and place individuals who are blind. Today, there are very few jobs which cannot be performed by blind persons with proper training and orientation. The Careers and Technology Information Bank (CTIB) maintained by the American Foundation for the Blind contains a database of legally blind people who perform a wide array of jobs ranging from accountants to physicians, from carpenters to computer programmers, from administrators to medical transcriptionists, and from farmers to chiropractors.

## Summary

While the quality and availability of services provided under the Rehabilitation Act, as amended, have improved dramatically over the last 75 years, we still have a long way to go in meeting the employment and independent living needs of our citizens who are blind. Even with the recent passage of the Americans with Disabilities Act (ADA), people who are blind or severely visually impaired routinely encounter discrimination and still face an unemployment rate that is estimated to range from 65 to 75 percent. Kirchner and Peterson (cited in Kirchner, 1988) point out that most working age blind or visually impaired people are not in the labor force. In fact, they estimate that only 31 percent are in the labor force (compared to 72 percent of the general U.S. population). For those who are employed, a substantial number are underemployed (i.e., working fewer hours than they would like or have jobs that are not commensurate in status, income, or challenge with their training, skills, and desires).

The Rehabilitation Act has greatly facilitated the vocational preparation and job retention for people who are blind or severely visually impaired.

From 1920 to the present, the state-federal rehabilitation system has been a flexible and increasingly effective mechanism for broadening and deepening the employment and independent living opportunities of individuals




Table 1

**Major Disabling Condition of Persons Rehabilitated by State Vocational Rehabilitation Agencies  
Fiscal Years 1925-1994**  
(Number of Persons)

Fiscal Year	Total Rehabilitated	Blindness and Other Visual Disabilities	Fiscal Year	Total Rehabilitated	Blindness and Other Visual Disabilities
1994	202,824	19,095	1959	80,739	8,690
1993	193,754	18,172	1958	74,317	7,915
1992	191,433	18,276	1957	70,940	7,773
1991	202,831	19,021	1956	65,640	7,395
1990	216,112	19,134	1955	57,981	6,623
1989	220,408	19,861	1954	55,825	6,533
1988	218,241	19,000	1953	61,308	7,455
1987	219,616	12,576	1952	63,632	7,750
1986	223,354	17,578	1951	66,193	8,165
1985	218,039	18,692	1950	59,597	7,090
1984	225,772	18,549	1949	58,020	7,061
1983	216,231	16,905	1948	53,131	6,200
1982	226,924	19,061	1947	43,880	5,182
1981	255,881	23,244	1946	36,106	3,859
1980	275,064	24,527	1945	41,925	4,945
1979	288,325	26,220	1944	43,997	5,489
1978	294,396	27,585	1943	42,618	4,723
1977	291,202	26,200	1942	21,757	1,791
1976	303,328	27,380	1941	14,579	1,131
1975	324,039	27,412	1940	11,890	895
1974	361,138	28,345	1939	10,747	705
1973	360,726	28,772	1938	9,844	648
1972	326,138	26,408	1937	11,091	678
1971	291,272	22,503	1936	10,338	752
1970	266,975	22,420	1935	9,422	692
1969	241,390	20,516	1934	8,062	546
1968	207,918	18,218	1933	5,613	404
1967	173,594	15,945	1932	5,592	388
1966	154,279	14,442	1931	5,184	381
1965	134,859	13,066	1930	4,605	312
1964	119,708	11,919	1929	4,645	315
1963	110,136	11,416	1928	5,012	376
1962	102,377	10,670	1927	5,092	374
1961	92,501	9,913	1926	5,604	445
1960	88,275	9,438	1925	5,825	399



who are blind or visually impaired. The challenge to the field of rehabilitation for the next 75 years is to systematically apply today's best practices to meet the needs and optimize the choices of blind or visually impaired people to become independent and fully integrated into the family, workplace, and community. 

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## AMERICAN Autumn-Winter 1995 REHABILITATION

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# Rehabilitation Facilities: A Perspective

Wes Geigel

**R**ehabilitation facilities, or community programs, did not arise in this country because of a national plan, because Congress created them, or because professional persons wanted a place to practice their skills. Rehabilitation facilities arose out of a concern by local leaders, parents, and advocates who perceived a real need for resources and services to assist people with disabilities in their home communities. Starting in the 19th century—long before government showed any interest—the private sector began to respond to this need by developing rehabilitation facilities, workshops, work centers, and extended employment facilities that were the forerunners of community programs we know today. Rehabilitation facilities now comprise a far-reaching, national network of private associations and service providers. This evolution is also a uniquely American phenomenon.

*The early facilities, in addition to providing services, also served as employers and did not place persons in industry.*

Dating back to the Middle Ages, the precursors of facilities were known as asylums in England, hospices in France, and in early colonial America as almshouses. In 1817, Gallaudet started a school for the deaf in the United States and, in 1832, the first facility for blind persons was started by the Perkins Institute for the Blind. The early facilities, in addition to providing services, also served as employers and did not place persons in industry. Later criticized for this failure, the fact is these facilities provided, at that time, the only employment and paychecks available for people with disabilities. After World War II, a number of medically oriented facilities were established that introduced psychological and social services in addition to physical restoration.

It wasn't until Commissioner Mary E. Switzer of the Vocational Rehabilitation Administration (predecessor to the Rehabilitation Services Administration—RSA) recognized that rehabilitation facilities represented a tremendous resource for the provision of services for people with substantial disabilities that the public sector responded to the need. Her interest launched the beginning of a private-public partnership that would ultimately expand and improve the utilization of rehabilitation facilities by the state vocational rehabilitation (VR) agencies on a fee-for-service basis. Ms. Switzer was instrumental also in the merger of the National Association of Sheltered Workshops and Homebound Programs and the Association of Rehabilitation Centers to form the then designated International Association of Rehabilitation Facilities (IARF, now known as ARA).

At that time, Commissioner Switzer appointed Henry Redkey as the new Director of the Division of Rehabilita-

tion Facilities. The Division was created in anticipation of the 1965 Amendments to the Rehabilitation Act. Based on a concept envisioned by Mr. Redkey, the Amendments included provisions that would lead to what became commonly known in the country as the "facility movement." Enacted as Sections 12 and 13 of the Rehabilitation Act, the concept became a reality embracing all of the needs for rehabilitation facilities. A major objective as stated in the purpose of the 1965 act included a mandate "to assist in the construction and improvement of rehabilitation facilities." To meet the need for new facilities, the act provided for State Facility Planning grants to help states in meeting the total statewide need for facilities. The act also authorized project development grants for community planning to meet the local need, as well as new construction grants based on the Hill-Burton formula (used for hospitals and related medically oriented facilities) to develop new and needed facilities to support the vocational rehabilitation program. For existing facilities, the act authorized facility improvement grants to help expand personnel and equipment to meet newly emerging standards, training services grants to help facilities that already met standards to provide services that would move people with disabilities outside the facility and into competitive employment, and technical assistance by highly specialized and capable consultants to assist facilities in upgrading any aspect of their programs. The act also established

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a National Policy and Performance Council to develop a new set of standards for workshops.

In a singular demonstration of personnel recruitment, Henry Redkey staffed the division with expert facility specialists from all over the country. Within a year, 44 state grants for facility planning grants were awarded, along with 54 facility improvement grants and 20 project development grants. A national training institute was launched and the National Policy and Performance Council was appointed. Facility specialists were employed in every state and held positions in all regional offices. The construction package was cleared and \$2.9 million worth of construction grants were awarded in the first year. In subsequent years, the Congress utilized Section 12 as a mechanism to earmark construction funds for specific facilities. Over a space of 11 years, millions of dollars were appropriated to award construction grants for private facilities in 13 different states. In addition, several new state owned and operated facilities were developed based on the existing Hot Springs, Arkansas, and Woodrow Wilson-Fishersville, Virginia, models. With a new set of standards adopted, published, and distributed by the National Policy and Performance Council, the Training Services Program came to life. Under the Technical Assistance Program, workshops were brought closer to industry with more than 60 representatives appointed to consult with regional panels. The project development authority also was utilized to provide planning and assistance to the new and growing independent living program. Similarly, some of the early supported employment projects were assisted as *workshops without walls*.

Research and demonstration grants were initiated and facility personnel training programs established in universities. It was decided also that, over the long term, standard setting should be a function of the private sector. With the assistance of research and development and facility improvement grants, the Commission on Accredi-



tation of Rehabilitation Facilities (CARF) was established, which together with the National Accreditation Counsel (NAC) became the main accrediting bodies for all facilities. Additional support was provided by the Council of State Administrators of Vocational Rehabilitation (CSAVR) in passing a resolution recommending that state VR agencies use only facilities accredited by CARF or NAC to

provide services for state agency clients. At that time, 28 percent of all case service funds were spent by state VR agencies to purchase services in rehabilitation facilities. Data indicate that by fiscal year 1990, the figure had risen to approximately 30 percent of Title I dollars, or \$275 million per year. In 1991, the most recent year for which data are available, the figure had risen to 34.7 percent. An additional 3 percent was spent on awarding establishment grants for renovation, new staff, and equipment. Throughout this period, ongoing liaison was maintained with private facility organizations. New accounting systems were developed. The Wagner O'Day Act—which focused on services for blind people—was amended to include people with other severe disabilities. The National Industries for the Severely Handicapped (NISH) was created to allocate government contracts for products and services to qualified workshops.

The initiative and impetus for facility growth originated with organizations that operated private facilities, including the National Easter Seal Society, Goodwill Industries, Jewish Vocational Services, the American Rehabilitation Association, United Cerebral Palsy, and





the Association of Retarded Citizens. Together, these organizations and their affiliates provided basic resources for the implementation of a variety of public programs including not only vocational rehabilitation, but employment programs administered by the Departments of Labor and Commerce, including the Economic Development Act, the Manpower Development and Training Act, the Comprehensive Employment and Training Act, the Job Training Partnership Act, the Developmental Disabilities Program, Title XIX and XX of the Social Security Act, Medicaid, Medicare, and Education for all Handicapped Children. The little coordination of these public programs that had been accomplished was done at the community level in the local rehabilitation facility.


In the 1980's, the term *sheltered workshop* came under scrutiny in some quarters on behalf of people with severe disabilities. These advocates maintained that workshops were segregating severely disabled persons from the mainstream of life and should be replaced by supported employment programs in integrated settings. In 1988, the National Institute on Disability and Rehabilitation Research (NIDRR) funded a major fellowship grant to conduct a national study of rehabilitation facilities and their involvement in integrated employment initiatives.

With the help of their parent organizations and I-NABIR, rehabilitation facilities also played an important part in implementing the Projects With Industry (PWI) program by serving as the bridge between rehabilitation and private industry. Many of the early PWI cooperative agreements were made with rehabilitation facilities, each of which established linkages to several private industries in their communities. PWI led to a focus on jobs in competitive employment and incorporated the talent and leadership of private industry as partners in the rehabilitation process. The national facility organizations adopted PWI and established national projects involving

the participation of numerous facilities throughout the nation.

This is a perspective from the past. Much of the history has been documented in the National Rehabilitation Association 1992 report entitled, *Rehabilitation Facilities: Preparing for the 21st Century*. Facilities have grown from individual local units to over 3,000 facilities serving as a tremendous national resource in implementing a variety of legislation. They have become a basic component and a partner in the rehabilitation process. The future direction must be determined by upcoming government administrators and by the national and local leaders in the voluntary community. The time is right to develop a national policy relating to rehabilitation facilities and to define the role of government in dealing with rehabilitation facilities and the world of work. Facilities are an indispensable resource in the best tradition of voluntarism. They are supported by local contributions, community resources, and the product of their own work. The only alternative is a massive, completely tax-supported public program.

There is no question that facilities and government are both evolving institutions in addressing the needs of people with disabilities. It is incumbent upon everyone involved to expand the citizen participation and public interaction with the government. Small steps are being taken. An evaluation contract has been awarded by RSA to assess the contribution facilities make and to determine, among other things, whether or not state agency fees are sufficient to pay the actual cost of services provided by facilities. But, if the needs of people with disabilities are to be fully met, it will be imperative to address the remaining barriers to private/public innovation and enterprise. Public policies should protect and encourage private resources. In dealing with the issues that face facilities, problems that confront facility directors every day—minimum wages, community relationships, employment, contract procurement, the range of services, fundraising, choices,

disincentives—must be explored and solutions identified and *implemented*. The concept of focusing on the people served rather than on the functions or the process of providing the service should be a subject of debate. Regardless of what facilities or community programs are called, the issues need to be addressed and national policies adopted. People with disabilities must be given choices and services tailored to meet their diverse needs in achieving individual, as well as national, legislative goals. 

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# Rehabilitation Research:

## Its Beginnings and Ongoing Contributions

*Katherine Seelman, Ph.D.  
Christian A. Levesque*

Federal interest and involvement in rehabilitation issues and policy dated initially from the Smith-Fess Act of 1920 (PL 66-236). Despite the appearance of this legislation shortly after the end of World War I, the Smith-Fess Act was specifically directed at rehabilitation needs of persons who were industrially disabled rather than those of disabled veterans. Later incorporated into the Social Security Act of 1935 (PL 74-271), the Smith-Fess Act marked the beginning of a state-federal partnership in rehabilitation medicine, research, and training that has been continually cited as optimal in succeeding testimony, amendments, bills, and acts.

***The rehabilitation research program, set in motion by the 1954 amendments was in full operation during the 1960s.***

In the changes to the 1954 amendments, the most fundamental was to change the public program from a single grant system to a multiprogram approach to disability and rehabilitation. In addition to the basic program of grants to states for providing vocational rehabilitation services to disabled people, a separate system of grants for research in rehabilitation and for training rehabilitation personnel was authorized.

The rehabilitation research program, set in motion by the 1954 amendments was in full operation during the 1960s. The program supported a great variety of experiments, analyses, and demonstrations in pursuit of new knowledge and better methods for restoring disabled people to activity and usefulness. To the program's official review body—the National Advisory Council on Vocational Rehabilitation—had come a parade of the nation's foremost people in rehabilitation, education, medicine, labor, and industry. Early in the decade, the first in a series of Rehabilitation Research and Training Centers was supported through the research program, assuring a number of "places of excellence" in which the expertise of a top flight center was combined with the resources of a university to assure maximum results in rehabilitation research, training of rehabilitation professionals, and care for people with disabilities. Through an extension of the rehabilitation law plus the 1960 "Health for Peace" Act, a program of international rehabilitation research was developed.

Under the International Health Research Act of 1960, funds accumulated in other countries from the sale of U.S. surplus commodities would become available for rehabilitation research. With these funds, the Vocational Rehabilitation Administration (predecessor to the Rehabilitation Services Administration) could join the United Nations, the International Society for the Rehabilitation of the Disabled, and the World Rehabilitation Fund in international rehabilitation research and expert exchange. Research and exchange of experts brought benefits to the United States from other countries, i.e., Polish techniques for prosthesis fitting and Yu-

goslavian approaches to teaching deaf children. By 1967, research activities were being carried on in Burma, India, Israel, Pakistan, Poland, Syria, the United Arab Republic, and Yugoslavia.

The Rehabilitation Research and Training Centers (RTC's) were inaugurated in 1962 with federal funding of medical RTC's at the University of Minnesota and New York University. Although the work of these two centers and those that shortly followed was not identified by statute as a "program" until 1973, authorization for this type of federal assistance to rehabilitation research, demonstration, and training activities had actually been included in legislation since the 1954 Amendments to the Rehabilitation Program (PL 83-565).

By 1968, there were 19 Research and Training Centers with a total budget of \$10.2 million. In the same year, 175 demonstration projects were funded at \$2.7 million. From such research, legislation was shaped to launch Regional Spinal Cord Injury Centers and Rehabilitation Engineering Centers.

During the 1970s, Congress and advocates at the federal level perceived a need for a separate agency that would focus on the research needs of people with disabilities. This need was met when Congress enacted Public Law 95-602—The Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendment of 1978—

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which created the National Institute of Handicapped Research (NIHR), which was initially staffed by research personnel from the Rehabilitation Services Administration (RSA). The research function was first created in 1954 within the Office of Vocational Rehabilitation (predecessor to the Vocational Rehabilitation Administration, which in 1967 became the Rehabilitation Services Administration, or RSA). The established goal of NIHR, as stated in the Amendment, was "to focus in one agency a strong commitment to carry on a major program of research on all aspects of disability and the attendant socioeconomic implications of the problems encountered by handicapped individuals." An early manifestation of NIHR's goal was the transfer of several key RSA research programs to NIHR: the Medical and Psycho/Social/Vocational programs, the Rehabilitation Training Centers, and the Rehabilitation Engineering Centers. Maintaining the largest single government-supported research portfolio, NIHR became the lead agency for coordinating disability research, demonstration, and other related activities. The scope of activities prescribed for NIHR, renamed the National Institute on Disability and Rehabilitation Research (NIDRR) in 1986, encompassed every facet of rehabilitation research

with no limitations in terms of type of disability, age, or intended goal.

All too frequently, technological devices designed to aid mobility or function for the disabled individual are either so cost-restrictive or so new that their existence is little known. To address this issue, the Technology-Related Assistance for Individuals with Disabilities Act of 1988 (PL 100-407) was enacted. This new legislation endeavors to place assistive technology in the hands of the disabled consumer by establishing a means of grant distribution to state government. As recipients of the technology assistance grants, the states are required to develop technology assistance programs on a statewide basis and to address seven areas of concern, including:

- increasing the awareness of the needs for and the effectiveness of assistive technology;
- increasing the availability of and funding for assistive technology devices and services;
- improving state policies and practices to facilitate the dissemination of technology; and
- increasing the probability that individuals of all ages will be able to obtain and use appropriate assistive devices and services.

Recent legislation also is responding to the need to extend civil rights protection to people with disabilities. Designed to provide a clear national goal of eliminating discrimination against people with disabilities, the Americans with Disabilities Act (ADA) of 1990 broadens the scope of federal civil rights laws to include people with disabilities and augments previous discrimination laws based on race, sex, national origin, and religion.

ADA more closely tracks existing laws that protect severely disabled individuals and specifies discrimination in the areas of employment, public accommodations, and public services. Specifically, the legislation prohibits disability-based discrimination in the workplace and requires most existing businesses to provide reasonable physical access to disabled persons.

NIDRR contributes to the independence of persons of all ages who have disabilities by seeking improved systems, products, and practices in the rehabilitation process. This is accomplished through grants, contracts, and cooperative agreements with universities, research groups, Indian tribes, non-profit organizations, profitmaking organizations, and individuals.

NIDRR activities are managed through several programs, each of which focuses upon different aspects of rehabilitation research and development, with the ultimate goal of improving the lives of people with disabilities. These programs include:

1. *Rehabilitation Research and Training Centers (RRTC's)*: This is NIDRR's largest program. Each center focuses on a particular aspect of the behavioral, medical, or vocational rehabilitation for people with disabilities. Some centers concentrate on a specific disabling condition, such as: deafness, low vision, spinal cord injury, or long-term mental illness. Others study activity areas important in the lives of people with disabilities, including independent living, housing service delivery, and information systems. Knowledge contributed by the RRTC's has greatly influenced the fields of rehabilitation medicine,





psychosocial rehabilitation, integration, vocational strategies, and architecture.

2. *Rehabilitation Engineering Centers (REC's)*: These centers seek solutions to disability-related problems through technology. Areas of study include sensory loss, mobility impairment, chronic pain, communication difficulties, the adaption of assistive devices, and technology transfer.

3. *Research and Demonstration Projects*: To address discrete problems outside the scope of the centers, NIDRR supports research and demonstration projects that seek solutions to specific problems encountered by individuals with disabilities and the professionals who work with them. Some of these have included model care systems for traumatic brain injury, the creation of a specialized data set for the collection of clinical and scientific information, and job development and placement for agricultural workers with disabilities.

4. *Dissemination and Utilization Grants*: Through this type of grant, the institute places information derived from research as well as the products of its grants and contracts in the hands of policymakers, rehabilitation practitioners, educators, technology developers, and persons with disabilities.

5. *Research Training and Career Development Grants*: These grants to institutions train physicians, therapists of various types, rehabilitation engineers, and other professionals in research methods and statistical analysis.

6. *Field-Initiated Research Program*: These projects allow NIDRR to fund activities that blend well with its overall mandate but which fall outside the usual range of priorities. Institutions of higher education, nonprofit organizations, and profitmaking businesses are eligible to apply for these grants.

7. *Innovative Research Program*: One-year grants, for a maximum of \$50,000, support inventive approaches to old and newly identified problems. These projects test new concepts, evaluate prototype aids and devices, develop and test rehabilitation training curricula and disseminate specific research findings. They provide the innovator with an opportunity to build and test a device or the new re-

searcher an opportunity to do pilot research that may lead to a multiyear grant.

8. *Research Fellowships*: Fellowships named for the late Mary E. Switzer are building future research capacity. NIDRR makes these grants on two levels. *Distinguished Fellowships* are awarded to individuals of doctorate or comparable academic status who have had 7 or more years' experience relevant to rehabilitation research. *Merit Fellowships* are given to persons in earlier states of their research careers.

9. *Model Spinal Cord Injury Systems*: These grants are competitively awarded to rehabilitation hospitals that operate first class spinal cord injury services and wish to carry on significant research related to improving the care, rehabilitation, and maintenance of spinal cord injured persons. A network of such centers has developed a national database.

10. *Small Business Innovative Research Programs*: New products useful to persons with disabilities and the rehabilitation field are encouraged through grants to small businesses. This three-phase program takes an idea from development to market readiness.

11. *Interagency Activity*: The Director of NIDRR chairs a statutory committee that provides a forum and a resource for all federal entities conducting or supporting rehabilitation research. The Interagency Committee for Disability Research promotes networking, information sharing, and cooperative efforts among its members and the programs they fund.

12. *Regional Disability and Business Technical Assistance Centers*: The Americans with Disabilities Act opens new opportunities for people with disabilities. It also places new responsibilities on employers, transit and telecommunication systems, state and local governments, and public accommodations. To assist in all these areas, NIDRR funds Regional Disability and Business Technical Assistance Centers. These centers provide technical assistance, training, and resource referral on all aspects of ADA. Their work is complemented by two other NIDRR ADA programs: four

Materials Development Projects and two National Peer Training Projects.

13. *International Programs*: NIDRR's legislation encourages active outreach for other countries with similar rehabilitation concerns. NIDRR cooperates in jointly-funded programs with India and Slovenia. It has also taken part in several projects with Russia in cooperation with the Department of State and other international agencies. NIDRR also conducts a worldwide program for the exchange of experts and information on rehabilitation.

14. *State Technology Assistance Grant Program*: The primary purpose of the Technology Act is to assist states to develop comprehensive, consumer-responsive programs in technology-related assistance for people of all ages with disabilities. The legislation is comprehensive. It contains seven purposes related to the State Grants Program for Technology-Related Assistance for Individuals with Disabilities. Through the State Grants Program, it is anticipated that participating states will:

- raise the awareness of the needs of people with disabilities for technology and support services;
- identify policies, practice, and procedures that facilitate or impede the availability of such technology and services;
- increase the availability of and funding for technology and support services;
- expand the awareness and knowledge of the efficacy of technology and support services among people with disabilities and those involved with them, including insurers and employers;
- augment the capacity of public and private agencies and other groups to provide technology and support services to those with disabilities;
- improve coordination among such agencies and groups; and
- increase the probability, during times of transition, that an individual will, to the extent appropriate, be able to keep technology and access support services that he or she needs.



## Examples of Products Developed by Grantees Funded by NIDRR

- *The Model Spinal Cord Injury System*, supported by NIDRR, contributes to the improvement of lives of persons with disabilities through the following mechanisms:

- maintenance of a national database which provides information on numerous issues, such as costs and outcomes over several years post traumatic injury;

- operating a system of care of persons with spinal cord injury (SCI) in several locations nationally;

- early admission to a Model Spinal Cord Injury System facility to assure reduction in medical complications and in hospital stay;

- followup comprehensive care after hospital discharge;

- assistance for ancillary services to provide a timely discharge to home or community;

- assistance in community integration (information on medical care, vocational support, accessible housing, accessible transportation); and

- provision of multicenter research concerning issues related to all aspects of rehabilitation for persons with spinal cord injury.

- *The Lighthouse, Inc.* was awarded a research and demonstration project to enhance the availability, accessibility, and effectiveness of rehabilitation services and technological resources for visually impaired and blind older persons in order to maximize functional independence and well-being in later life. This project will provide an accumulated fund of knowledge about programs and services for visually impaired older adults. This knowledge is critical to consumers, families, service providers, and planners as they prepare for the continued increase of this population. A national survey of programs and services will document the current status of service delivery to visually impaired older persons and describe model programs and their development. A low vision curriculum targeted to generic health and human service providers, to be devel-

oped and tested, will offer a systemic assessment of the impact of low vision training on non-eye care professionals. The expertise of state program directors and agency executives in the development of programs funded under the Older Blind Independent Living Program will be tapped along with that of program consumers in a series of focus groups intended to pinpoint effective strategies for program delivery under this appropriation.

- *Adaptive Communication Systems* (ACS) markets a new evaluation and training aid for children and adults with low cognitive/physical skills. The *Flexi-Formboard* assists in shaping recognition skills needed in early education and in future cognitive development. The product was developed by the Smith-Kettlewell Eye Research Institute, San Francisco, California.

- *The Center for Accessible Housing*, School of Design, North Carolina State University, Raleigh, North Carolina, has produced a catalog featuring six house plans that incorporate universal design principles that make the home accessible by persons who use wheelchairs and other mobility aids. The plans include thoughtful and well-planned features that make the house livable for everyone.

- New digital and semi-digital programmable hearing aids, computer-assisted hearing aid prescription methodology, and the development and evaluation of acoustic amplification systems using FM radio transmission embody features based on research performed at the *Lexington Center*, Rehabilitation Engineering Research Center (RERC), Jackson Heights, New York. These important features incorporated in programmable hearing aids and other acoustic devices are now available from several hearing aid manufacturers through audiology and otolaryngology professionals.

- *The University of Delaware Rehabilitation Engineering Research Center*, Dover, Delaware, has developed improved synthetic speech that meets the needs of persons with communication impairments. These synthesizers have been incorporated into "RealVoice" that

is being marketed by Adaptive Communication Systems.

- *The Vermont Rehabilitation Engineering Center*, Burlington, Vermont, has developed a number of products important in the rehabilitation of persons with low back disabilities. These include:

- The Vermont Spinal Fixator*

- Lordosimeter*

- Intervertebral Motion Device*

- Ergonomic Lifting Calculator*

- The Liftbox* (TM)

- A Three-Axis Electrogoniometer: The BackTracker* (TM);

- The BackCycler* (TM)

- Pressure Monitor*

- Smart Corset*

Information on obtaining devices may be obtained from the Vermont Rehabilitation Engineering Center, University of Vermont.

- A textbook entitled *Geriatric Rehabilitation* has been written and edited by the staff of the *Research and Training Center on Aging* at the Rancho Los Amigos Medical Center, Downey, California. The textbook is being used by universities to emphasize the nature of interdisciplinary rehabilitation process for older individuals and is directed to students in counseling, social work, occupational therapy, and other disciplines.

- *The Rehabilitation Engineering Research Center on Technology for Children*, Rancho Los Amigos Medical Center, Downey, California, has developed an improved articulating ankle joint which enables children to walk better. A contracture reduction orthosis reduces knee contractures in children, enabling them to proceed with gait training. Guidelines on use of an integrated controller for power wheelchairs have been developed and published in *Assistive Technology*, *RESNA News* and *TeamRehab Report*.

- *The Model Traumatic Brain Injury Model System* at TIRR, Houston, Texas, has produced *The Brain Injury Glossary*, now in its 5th edition. This publication has become widely accepted as the primary source of definitions in the area of brain injury rehabilitation. It is disseminated by the National Head Injury Foundation, by the Ontario Canada Head Injury Foundation, and several national insurance companies in the



United States. This widespread dissemination and utilization affords standardization of terms and definitions.

- *The American Foundation for the Blind*, Atlanta, Georgia, through a research and demonstration project is developing *Adult Braille Literacy Empowerment Guidelines* (ABLE-G)> Nine studies, instructor objectives, review of existing braille curricula, review of existing braille technology, guidelines for quality programs and practices, fund raising, and material acquisition. ABLE-G was piloted in seven sites. The revised version of ABLE-G is being disseminated to some 200 sites.

- *Children's Hospital*, Boston, Massachusetts, through an NIDRR funded project has tested successfully a new approach for interventive and preventive work in the newborn intensive care unit (NICU). The model developed and tested can prevent and/or reduce the degree of brain hemorrhaging and its lifelong sequelae of spasticity, learning disabilities, mental retardation, and the degree of chronic lung disease and its lifelong sequelae of developmental disability.

- Under the original Technology-Related Assistance for Individuals with Disabilities Act (the Tech Act), the National Institute on Disability and Rehabilitation Research awarded funds to *Amtrak* to design and develop a lift to make railroad cars for long distance and commuter trains wheelchair accessible. Amtrak began with a hand-operated mechanical lift which was heavy and timeconsuming to operate. A subsequent award through a competition was made to *Stewart and Stevens Engineering*, Commerce City, Colorado, to develop and test a prototype electronic lift. This prototype will be tested on trains running between Chicago and Milwaukee. Further activities by Amtrak include designing wider doors for railroad cars and accessible bathrooms for its trains.

- *ABLEDATA* is now one of the most important national sources of information on assistive technology and the manufacturers of products for persons with disabilities. An extensive outreach program has resulted in monthly columns by ABLEDATA staff members in *Accent on Living* and *Exceptional Parent*, as well as articles in the *New York Times*, *Forbes*,

and numerous other general and specialized press. In 1994, calls to ABLEDATA averaged 700-800 per month. Since the recent spate of publicity, calls have increased to 1,354 per month. Media Pacific, Inc., a Korean firm, purchased a CD-ROM copy of ABLEDATA with the intent of making it available to 500,000 online users. ABLEDATA also has been approached by a firm in Michigan to incorporate it as part of a software system they have developed that is run on 52 Michigan Employment Security Commission Networks throughout the state as well as in Florida, Illinois, Maine, Massachusetts, and Pennsylvania. The Oregon Museum of Science and Technology asked for a copy of the ABLEDATA database for use in a kiosk-style information center at the museum.

- *The National Rehabilitation Information Center* (NARIC) assists persons with disabilities, researchers, professionals, employers, businesses, and others to find relevant literature, reports, articles, audiovisuals, and database searches according to their needs. NARIC is heavily used. For example, for March 1994, NARIC information specialists answered 4,805 requests for information and services from 1,795 patrons. Of these patrons, 37.8 percent were individuals or family members of individuals with disabilities. On the Internet, the Cornucopia of Disability Information (CODI) accessed on World Wide Web, points inquirers to NARIC and its product, *Directory of National Information Digest of Data on Persons with Disabilities*. The connections on the Internet node are promising; for example, for November 4-10, 1994, there were 10,945 connections. There were over 1,200 different Gopher or World Wide Web servers pointing to CODI. Twelve of the hosts connecting were freenets, community computer systems that allow anyone with a modem to access Internet, usually at no cost or low cost. The operator of CODI estimated that there would be 570,703 CODI connections in 1995.

- *The Cooperative Database Distribution Network for Assistive Technology* (CO-NET), based at the Trace Research and Development Center, Madison, Wisconsin, reports the availability of

CO-NET CD-ROM (updated regularly), which includes a demonstration of the Trace Cooperative Electronic Library. This CD gives access to several *Cooperative Service Directories* (statewide and national listing services for persons who are disabled) and is for use with Macintosh and IBM systems. The software and databases are the result of many people at several agencies, with major sponsors being Apple Computer, Inc.; IBM Corporation; and the National Institute on Disability and Rehabilitation Research.

Microsoft Windows NT Workstation Beta Release and AccessDOS (IBM/PC & IBM/ps/2) provide software accessibility for users with disabilities. A Microsoft AccessPack has been created which can be added at the user's option. The AccessDOS provides extended keyboard, mouse, and sound access for DOS users, especially helpful to persons with disabilities. These software packages were developed at the Trace Research and Development Center, Madison, Wisconsin.

- *The Motion Picture Access Project* at CPB/WGBH National Center for Accessible Media, Boston, Massachusetts, has codeveloped a system of displaying closed captions in movie theaters. The *Reflected Captioning System* involves the use of a light-emitting diode mounted in the rear of a movie theater. Special software enables the device to display reversed text. Captions are viewed on an adjustable gooseneck arm.

The project has also developed captioning software for displaying closed captions in live theater environments ("VFDCp" Windows software) and in movie theater environments ("Motion Picture Scheduler" DOS software). The *Reflected Captioning System* has been installed at the Langley IMAX Theater, National Air and Space Museum, Washington, DC, and VFDCap is being used at Arena Stage, Washington, DC.

- *Southwest Disability and Business Technical Assistance Center on the Americans with Disabilities Act* (SWDBTAC), located at the Independent Living Research Utilization Program at TIRR, Houston, Texas, has produced a number of documents for dissemination to individuals with disabilities and all levels



of personnel concerned with rehabilitation of such individuals. Materials prepared at SWDBTAC as well as materials from other DBTACs have been translated into Spanish for appropriate distribution. The materials are available from The Institute for Rehabilitation Research, Independent Living Research Utilization, SWDBTAC (Region VI).

- *The Beach Center on Families and Disability*, University of Kansas, Lawrence, has developed over 190 products since 1988, each available in alternative forms—books, book chapters, monographs, annotated bibliographies, training manuals, journal articles, videotapes, audiotapes, fact sheets, research briefs, newsletters—that are now being used by individuals with disabilities, their families, service providers, policymakers, researchers, businesses, and others.

Some examples include:

- a videotape, *Life After High School for Students with Moderate and Severe Disabilities: Great Expectations and Practices*;

- two parent resource directories: *Parent to Parent: A Treasury of Best Practices* and *Parent to Parent National Resource Directory*;

- a program rating scale for service providers: *Family-Centered PROGRAM RATING SCALE (FAMPRS)*; and

- a recently published book, *Exceptional Lives: Special Education in Today's Schools*.

Parents of children with challenging behavior are able to use the Beach Center's Family Connection Hotline which provides information and referral nationally to assistance locally. State-of-the-art information is disseminated to service providers nationally. The Beach Center studies document the positive contributions persons with disabilities make to their families, friends, and society.

- *The Washington Business Group on Health* has published a book entitled *Disability Management—A Complete System to Reduce Costs, Increase Productivity, Meet Employee Needs, and Ensure Legal Compliance*, written by Don Galvin, Ph.D. Another project, *Case Management: Improving Employment Opportunities for People with Disabilities and Developing a Cost-Benefit Model*, resulted in the publication of a brochure entitled,

*Disability Case Management: A Return-to-Work Guide for Consumers*.

- Among the activities at the *University of Arkansas Research and Training Center in Vocational Rehabilitation* were *Career and Rehabilitation Planning*, *Assessment for Personal Choice*, *Return-to-Work*, *Transition for School to Work*, *Independent Living Based Employment Interventions*, and *National Employment Preparation Agenda*.

- *The University of California at San Francisco* conducts a utilization project focusing on disability statistics. Two of the products available from the project and from NIDRR are *Disability Statistics Abstracts* and *Chartbook on Disability in the United States*.


- *The Research and Training Center on Public Policy in Independent Living* at the World Institute on Disability is now printing the second edition of *A Brief Summary of Legislation Affecting Persons with Disabilities*. This is the only publication of its kind currently in print, which summarizes legislation, highlights recently enacted laws, and recommends sources for further indepth information. It has been found to be an indispensable tool for those whose work is influenced by disability and law.

- NIDRR funded a project for the *Foundation for Children with AIDS* in Roxbury, Massachusetts, entitled, *Evaluation of Project STAR: A Family Centered, Community Based Program for Children with HIV Infection and Their Families*.

- *The Advocado Press, Inc.*, will conduct indepth training at three national disability gatherings on working effectively with the media. This type of training has never before been conducted for disability rights groups nationwide and will provide an opportunity for groups to learn effective techniques for getting reporters interested in and covering disability issues from a rights, rather than charity, perspective. The project brings together *The Advocado Press* and *Eil Sof Communications*, who, as a result of this training, will produce a workbook for use by groups inhouse to learn effective techniques for working with media on disability issues coverage.

*ORCCA Technology, Inc.*, will develop, fabricate, and field test an adaptable scanning selection aid (ASSA) and application accessories. The ASSA system will provide persons with limited motor function or minimal verbal communication skills a means of making choices in their environment through the use of simple switches. The ASSA consists of a transmitter unit, a receiver/control unit, and an array of lighted indicators which are scanned in a sequential fashion. The ASSA will be designed to incorporate a wide variety of features, including support for remote or direct switch control; choice of three modes of scanning (automatic, manual, and inverse); choice of the number, color, size, physical arrangement of lighted indicators, and the scan rate; and the ability to operate with many types of simple switches. The ASSA will meet two essential needs: a simple, yet adaptable, switch-operated scanning communication aid which can be used in a wide variety of environments for making simple choices and an assessment and training device for use with persons in transition from simple switch applications to more sophisticated scanning computer and communication systems.

- *American Research Corporation of Virginia* will develop a device that displays graphics in a form that can be easily interpreted by blind and visually impaired computer users. This device will be a tactile array that conveys sufficient information on a display that is of a size practical for office use. During this phase of the project, ARCHIVE will develop the device and the necessary software at its Redford, Virginia, installation. The system will then be evaluated by computer users at a research laboratory in Louisville, Kentucky, who are visually impaired.

The accomplishments of the federal rehabilitation research program, since its inception to the present, have gone a long way towards fortifying and giving new directions to the state-federal vocational rehabilitation program. Current and recent projects promise to continue the all important task of providing comprehensive services to people with disabilities, as the program prepares for the 21st century. 



# A Legislative Perspective on the Rehabilitation Act

*The purposes of this Act are—*

*(1) to empower individuals with disabilities to maximize employment, economic self-sufficiency, independence, and inclusion and integration into society through—*

*(A) comprehensive and coordinated state-of-the-art programs of vocational rehabilitation;*

*(B) independent living centers and services;*

*(C) research;*

*(D) training;*

*(E) demonstration projects; and*

*(F) the guarantee of equal opportunity; and*

*(2) to ensure that the Federal Government plays a leadership role in promoting the employment of individuals with disabilities, especially individuals with severe disabilities, and in assisting States and providers of services in fulfilling the aspirations of such individuals with disabilities for meaningful and gainful employment and independent living.*

*— The Rehabilitation Act of 1973, as amended*

Beverlee J. Stafford

The above purpose statement from the Rehabilitation Act of 1973 was most recently amended by the Rehabilitation Act Amendments of 1992 (P.L. 102-569). This purpose statement articulates the major themes inherent in the act since its last major overhaul in 1973. The themes of consumer empowerment and choice, services to individuals with severe disabilities, integration, independence, self-sufficiency, and civil rights for individuals with disabilities had their genesis in the 1973 act. However, these themes have been refined, strengthened, and expanded through each subsequent reauthorization and amendment to the act, culminating in the significant changes seen in the 1992 amendments.

## The Rehabilitation Act of 1973

The Rehabilitation Act of 1973 (P.L. 93-112) was a landmark piece of legislation for individuals with disabilities. The 1973 act replaced the former Vocational Rehabilitation Act and refocused the state vocational rehabilitation (VR) services program on serving those individuals with the most severe disabilities (then called "handicaps"). Congress was concerned that, as a result of the War on Poverty initiative in the 1960's, the program was serving many individuals who were welfare recipients that were deemed to be socially disadvantaged or individuals who had behavioral disorders but were not necessarily disabled. While it was commendable that social programs addressed the needs of these individuals, Congress felt that this population was

not and should not be the primary focus of the VR program.

The Rehabilitation Act of 1973 was the genesis of many of the fundamental concepts that we now take for granted. The 1973 act introduced many of requirements that are currently part of the established state VR services program. The act required that each individual who is determined eligible for services have in place an *individualized written rehabilitation program* (IWRP) that is jointly developed by the individual and the VR counselor. The individual with a disability was guaranteed a voice in the development and implementation of his or her plan of services. The 1973 act also introduced a requirement for individuals with disabilities to have access and input to policymakers in the state agencies that provide services to them. Both of these requirements have been strengthened through subsequent reauthorizations of the act.

The Rehabilitation Act of 1973 also included provisions that guaranteed the rights of individuals with disabilities. Growing out of the expanding disability rights movement, Title V of the act provided several mechanisms to guarantee nondiscrimination on the basis of disability in federally funded programs. These provisions, including Sec. 504 that prohibited discrimination on the basis of disability in employment settings, were the early models of

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civil rights guarantees that culminated in the Americans with Disabilities Act that was enacted in 1990.

Along the same lines, the 1973 act introduced the first Client Assistance Projects (CAP's), which were authorized as a pilot effort to develop ombudsman models to assist clients of the state VR agencies in their relationships with those agencies. Again, this was another concept that was introduced in 1973, but has steadily grown over the years into a strong advocacy program for individuals with disabilities.

### **The Rehabilitation Act Amendments of 1978**

It would be remiss to describe the 1973 act without a brief discussion of legislative actions that preceded its passage. In 1972, bills were introduced in the House and the Senate to reauthorize the Vocational Rehabilitation Act. While the House and Senate reached agreement on the legislation on two occasions, President Nixon twice vetoed these bills. In both instances, the Senate failed to override the Presidential vetoes.

The proposed legislation contained many of the provisions that were eventually passed in the Rehabilitation Act of 1973, with one notable exception—the 1972 bills contained a new program that focused on independent living services for individuals with severe disabilities. The administration feared the escalating costs of a program that would seek to provide for the needs of individuals with disabilities in the areas of housing, transportation, assistive devices, modifications, etc., in order to assist those individuals to live independently in the community. While the introduction of this program delayed the passage of the 1973 act, it certainly called attention to the need for such a program, which is now firmly established in all states. However, the independent living (IL) program has never been funded at a level commensurate with the needs of individuals with severe disabilities. The program relies on systems advocacy, peer counseling, and other mechanisms to achieve its objectives, since funding is limited.

In response to the Presidential vetoes, a comprehensive IL program was not included in the 1973 act; however, a study of the need for such a program and pilot projects were authorized. Subsequently, the 1978 Amendments to the Rehabilitation Act (P.L. 95-602) authorized a program of comprehensive services for IL for individuals with severe disabilities. A new title VII was added to the act containing four parts:

- a state program for IL services to be conducted by the state VR agency;
- a program of local, community-based centers for independent living (CIL);
- an IL program for older blind individuals; and
- a protection and advocacy program for all programs and projects funded under the Rehabilitation Act.

As is the case with other provisions in the Rehabilitation Act, the IL program has grown substantially since the 1970's through many reauthorizations that have increased the role of the CIL's as major players in the disability rights movement.

In addition to the creation of Title VII—Independent Living—the 1978 amendments contained another important provision that sought to expand upon the rights and remedies for individuals seeking and receiving VR services. These amendments established a formal appeal mechanism for when an individual disagreed with a VR counselor's determination on eligibility for or the delivery of services. The individual was now entitled to a fair hearing with a written final decision from the state agency director. If the individual was not satisfied with that decision, the individual could then request a review of the appeal and the decision by the Secretary of the Department of Health, Education, and Welfare (which then housed the Rehabilitation Services Administration). The Secretary could make recommendations to the state director on the matter but did not have the authority to overturn or modify the state director's final decision. This is based upon other provisions in the act that require that the state director have final decision au-

thority that cannot be delegated to any other agency or individual.

### **The Rehabilitation Act Amendments of 1984**

The Rehabilitation Act Amendments of 1984, Public Law 98-221, greatly expanded the role and function of Client Assistance Projects, hereafter to be known as Client Assistance *Programs*. CAP's would now be in all states and funded through formula grants—not discretionary project monies. The amendments mandated that each governor designate and agency within the state to operate a CAP as a condition for the receipt of the state's grant award for the state VR services program. The role of CAP broadened to assisting clients and client-applicants of *all* programs and projects under the Rehabilitation Act—no longer just those individuals that are receiving VR services. This meant that CAP's would be dealing with issues under CIL's and other IL programs, Projects With Industry (PWI), Migrant Workers and American Indian projects, and all other programs and projects that provide services under the act. The amendments also required that the governor must assure that the designated CAP agency have the authority to pursue administrative and legal remedies on behalf of the clients and client-applicants that it serves.

The 1984 amendments had specific requirements for the designation of CAP agencies. The amendments allowed states to "grandfather" in those existing Client Assistance Projects that were housed within state VR agencies, but mandated that, in those states that did not have existing projects, the designated agency to operate the CAP must be an agency that is independent of any agency or organization that provides services under the Rehabilitation Act. Many governors designated the existing Protection and Advocacy (P&A) agency to operate the CAP—especially in those states that did not have an existing CAP project.

Because many P&A agencies were now designated to operate CAP programs, the overall character of CAP



began to evolve from ombudsman programs into more advocacy-oriented efforts. The P&A agencies, as well as other designated CAP agencies that were outside of state agencies, began to test the limits of the 1984 amendments and move the CAP program into advocacy issues beyond its previous role within the state VR agency service delivery structure. Subsequent reauthorizations reflect this movement.

Another major change in the 1984 amendments was the requirement for the development of evaluation standards and performance indicators for two programs—Centers for Independent Living and Projects With Industry. This reflects Congress's interest in making programs more accountable and results oriented. Again, this interest continues through subsequent reauthorizations of the act.

### **The Rehabilitation Act Amendments of 1986**

These amendments (P. L. 99-506) created a new state formula program for *supported employment* services in response to demands from the disability community that this new approach was needed for serving severely disabled individuals. While the research focused mainly on the usefulness of this approach for individuals with developmental disabilities—especially individuals with mental retardation—the supported employment model was seen as valuable for other populations, including those individuals with mental illnesses who can benefit from transitional employment models.

Each state would now receive formula grant funds, that did not require any state matching monies, to provide supported employment services. Discretionary grant funds were also available on a competitive basis to establish statewide change projects. The concept of supported employment is that an eligible individual will need some sort of worksite supports throughout the term of his or her employment. Therefore, the formula program created under the Rehabilitation Act was seen as providing time-limited services and that other

public agencies or nonprofit organizations would then pick up the costs of supported employment after the state VR agency completes its time-limited course of services.

The 1986 amendment also made significant revisions to the due process requirements related to the receipt of VR services. An individual who is dissatisfied with any decision or determination made by a VR counselor could now seek a hearing before an impartial hearing officer (IHO). The decision of the IHO would still be subject to review by the state director of the VR agency who maintains the authority to overturn the IHO's decision based upon established standards for such review. The Secretarial review process that was instituted in the 1978 amendments was eliminated—leaving the state director's review as the final step prior to an individual seeking remedy through the courts.

For the first time, the 1986 amendments required that state agencies conduct public meetings to discuss and take input and comment on the state plan for VR services. These public meetings must be held across the state and sufficient notice must be provided so that interested parties can attend and provide input. The amendments of 1986 also made significant changes to the CIL program under Title VII. Congress, in response to advocates in the IL movement, mandated that each CIL have a governing board whose members include a majority of individuals with severe disabilities. This shows Congress's commitment to consumer control in programs under the act—especially IL programs. A fundamental tenet that expands further in the 1992 reauthorization.

### **The Americans with Disabilities Act of 1990**

The Americans with Disabilities Act (ADA) made several minor changes to the Rehabilitation Act. The modifications were in definitions that apply to the civil rights provisions in Title V of the Rehabilitation Act, in order to make

those definitions consistent with the ADA provisions.

However, the impact of ADA was felt throughout the disability and rehabilitation communities. The promise of nondiscrimination and equal opportunities for individuals with disabilities as guaranteed under ADA has yet to be fully realized. When discussing the 1992 reauthorization of the Rehabilitation Act, certain factions in Congress were to have said that ADA is the skeleton—and that the Rehabilitation Act would be "the meat on its bones."

### **The Rehabilitation Act Amendments of 1992**

On October 26, 1992, Public Law 102-569 was enacted that contained the most significant amendments to the Rehabilitation Act since the act was created in 1973. In one view, the Rehabilitation Act Amendments of 1992 made many pivotal changes to the act. In another view, one could argue that the 1992 amendments only continue to carry forward the major tenets of the 1973 act in terms of focusing on the individuals with the most severe disabilities, guaranteeing rights and remedies, and expanding consumer input and choice in the programs under the act.

For the first time, the act requires that states define who are the individuals with the most severe disabilities. Priority must be given to these individuals—especially if the state is under an order of selection for services. The amendments also clarify that only those individuals with the most severe disabilities are eligible for supported employment services. Also for the first time, the act now contains a definition of an *employment outcome* for individuals with disabilities. This definition gives priority or emphasis to full-or part-time competitive employment in the integrated labor market or any other vocational outcome as defined by the Secretary of Education through regulations.

The 1992 amendments made changes in the act to conform the Rehabilitation Act with other existing laws. For example, definitions were either changed or included for the first time to make the



terms and definitions under the Rehabilitation Act consistent with ADA, the Individuals with Disabilities Education Act (IDEA), and the Assistive Technology and Services for Individuals with Disabilities Act (Tech Act).

Another major focus of the 1992 amendments is on accountability. Along those lines, the amendments contain a new requirement for evaluation standards and performance indicators for the state VR services program. These standards and indicators must focus on outcome measures; failure to meet such standards and indicators would result in the development of a performance improvement plan.

Public Law 102-569 expands opportunities for informed choice for individuals with disabilities and for consumer input in policymaking for programs and projects under the act. At the individual services level, the act requires that the Rehabilitation Services Administration (RSA) promulgate regulations in a timely manner to expand upon what informed choice means for individuals receiving services under an IWRP. Other provisions were included to require consumer choice in the selection of vocational goals, services, and service providers under the state VR services program.

A new demonstration program was established by the amendments for projects to increase client choice in services and service providers. Seven demonstration programs were subsequently funded and are now in place. An evaluation of these projects has begun, and it is hoped that these projects will yield significant information for the next reauthorization of the Rehabilitation Act planned for 1997.

At the system level, a *State Rehabilitation Advisory Council* is mandated for each state VR agency that is not already subject to a consumer-controlled board or commission. The state Rehabilitation Advisory Council has significant consumer representation and is involved in the development and review of the state plan for VR services. The council has other roles and functions—including a requirement to conduct consumer satisfaction surveys. Other

mechanisms for consumer input in policymaking have been strengthened, and requirements for public meetings on the state plan were clarified in that the meetings must be conducted prior to the development of the plan.

The most significant expansion of consumer input requirements was the establishment of the *Statewide Independent Living Council*. This council has a much more substantial role in policymaking for IL programs than the State Rehabilitation Advisory Council does for VR programs. The Statewide Independent Living Council is consumer

***A new emphasis on populations that are traditionally unserved or underserved was included in the act by the 1992 amendments.***

controlled and must *jointly* submit the state plan for IL along with the VR agency or agencies in the states. This means that this council has a significant role in deciding how the funds for IL services will be spent within a state.

Another area of emphasis in the 1992 amendments was an attempt to streamline requirements. Because many consumer and advocacy groups were concerned about the time it takes to establish eligibility for VR services and the amount of time and money spent on testing and evaluation, the 1992 amendments require that eligibility be established within 60 days of application and that state agencies rely, to the extent appropriate, on existing medical and other information to establish and document eligibility for services.

Consumer and advocacy groups were also concerned that state agencies were not serving those individuals with the most severe disabilities. In re-

sponse to this concern, the 1992 amendments establish a presumption that an individual can benefit from VR services in terms of reaching an employment outcome. A state VR agency would have to establish clear and convincing evidence to refute this presumption. The 1992 amendments also make clear that state VR agencies can assume that an individual who is receiving social security benefits (SSDI and/or SSI) can be presumed to have met certain elements of the eligibility criteria but make clear that eligibility for VR services is still determined on an individualized basis. These changes to the eligibility criteria have served to greatly expand the universe of individuals who are eligible for VR services.

A new emphasis on populations that are traditionally unserved or underserved was included in the act by the 1992 amendments. New requirements for outreach and services to traditionally unserved and underserved populations were included in almost all programs and project authorities under the act. In addition, the 1992 amendments required a 1 percent set aside from funds appropriated for Titles II, III, VI, VII, and VIII to be used to recruit minority individuals into the field of rehabilitation; to financially assist historically black colleges and universities and other institutions of higher education whose minority enrollment is 50 percent or more to prepare students for careers in rehabilitation; and to provide outreach and capacity building to minorities entities, including institutions of higher education and nonprofit and for profit agencies.

The evolution of CAP programs continued in these amendments with the inclusion of the term *advocacy* for the first time. These programs can now advocate for individuals seeking or receiving services under the Rehabilitation Act. CAP programs can also provide information to these individuals and the general public about the employment-related provisions under Title I of ADA. CAP's can also assist and advocate with regard to any service that will facilitate employment for an individual.



Besides the expansion of the CAP mandate, the 1992 amendments greatly expanded the *Protection and Advocacy for Individual Rights* (PAIR) program. This authority began as a discretionary grant program under Title VII (IL) of the act. It is now a formula grant program under Sec. 509, and each state has received PAIR funding. The agency designated to operate the PAIR program is the same agency as designated by the governor to administer the P&A program under Part C of the Developmental Disabilities Assistance and Bill of Rights Act. The 1992 amendments also broadened and clarified the role of the PAIR program. This program's broad mandate is to protect the legal and human rights of individuals with disabilities who need services that are beyond the services provided by the CAP, and who are also ineligible for services from other existing P&A programs.

A major emphasis throughout the 1992 amendments is the integration of individuals with disabilities into society. This links back closely to the major provisions of ADA that individuals with disabilities must be afforded access to all aspects of American society—from public accommodations to education, to communications, and to employment. As noted above, the amendments give priority and emphasis to competitive employment in the integrated labor market. This emphasis on integration carries over into the methods for the delivery of services. The term *rehabilitation facility* was replaced with the broader term *community rehabilitation programs* to acknowledge that services were being provided in alternative settings, especially settings in the community as opposed to segregated settings in facilities. The amendments add new IWRP provisions related to documentation of placements in integrated settings and mandate that assessment be carried out in the most individualized and integrated settings, consistent with the informed choice of the individual.

A final, but important, change brought about by the amendments is in the area of due process. The state director's review of the IHO decision is now limited to only issues that the di-

rector determines, based on clear and convincing evidence, are clearly erroneous and contrary to federal or state law or policy. The amendments also provide for more specificity in the selection of IHO's and in the qualifications for IHO's.

## Future Amendments and Reauthorizations


The current Rehabilitation Act of 1973, as amended, expires in 1997.<sup>1</sup> RSA is just beginning its process to solicit input to develop a proposal for the reauthorization of the act. The current political environment, as well as issues confronting consumers and service providers, will no doubt affect the next reauthorization.

The impact of work force development and job training consolidation legislation that was passed by both Houses in Congress in 1995 is not yet known. Those bills are currently in conference. It is too soon to speculate on the effect that these consolidation efforts will have on services to individuals with disabilities under the Rehabilitation Act. In fact, many of those new proposed provisions would not go into effect until 1998—which is beyond the scheduled reauthorization of the act.

It is also likely that other legislative and executive branch initiatives will have significant impact upon public disability policy. Efforts to streamline requirements, to reduce burden on grantees and the public, to consolidate funding streams, to promote *one-stop shopping*<sup>2</sup> and/or *no wrong door approaches*<sup>3</sup> will all be factors in the next reauthorization. The interest in accountability, outcomes, and results will continue. A current Administration initiative to utilize *performance partnership agreements*<sup>4</sup> may replace the usual granting mechanisms and require that states and local providers guarantee results for the federal dollar.

In addition, consumer and advocacy groups will demand more involvement and better operationalization of consumer choice in rehabilitation programs. Service providers will offer alternatives to the existing service

delivery system. IL programs will seek more direct control of service dollars. CAP and PAIR programs will seek to expand their mandates to assist and advocate for individuals with disabilities. Employment disincentives and attitudinal barriers will still limit employment opportunities for individuals with disabilities unless major changes are evident in the overall public disability policy structure.

Does all of this mean major reforms for the programs under the Rehabilitation Act? It may or may not—depending upon your view. If you think, as I do, that the Rehabilitation Act and its amendments reflect the evolution of the disability rights movement in this country since the 1970s—then the next reauthorization is just another milestone in that quest. Consumers will have more choice, input, and perhaps even control of programs that directly affect their lives. CAP and PAIR programs will have broader mandates. Due process requirements will be strengthened. Settings for service delivery and employment outcomes will be integrated in the community. People with the most severe disabilities will have better access to individualized services that meet their needs and their interests. Individuals who have traditionally been excluded or underserved by programs under the act will have improved access. As you can see, all of the above issues had their roots in the Rehabilitation Act of 1973. Each reauthorization or amendments brought those issues closer and closer to the realization of full integration of individuals with disabilities into American society—with all related rights and benefits. 

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The author will like to express special thanks to Terry D. Conour, RSA Region V Commissioner, for his paper, *Historical Background of Vocational Rehabilitation in the Twentieth Century*, which was invaluable in the development of this article.



## NOTES

1. Technical amendments to the Rehabilitation Act were passed in 1993, and minor amendments to the Rehabilitation Act have been made by other laws since that time.

2. *One-stop shopping*: efforts under a work force development consolidation to allow a consumer access to a variety of job training and placement activities through one entry point.

3. *No wrong door approaches*: efforts to coordinate intake for a variety of job training and placement programs so that a consumer can access any or all of these programs through any application or intake process.

4. *Performance partnership agreements* are agreements that are entered into by the Federal Government and a state or local partner that specify the particular outcomes that the Federal Government is seeking. The state or local partner is allowed much flexibility to reach those outcomes in whatever means are appropriate and effective.

## A History to be proud of

*Continued from inside front cover*

with disabilities are assisted in entering or returning to employment each year. We have a proud and distinguished history of accomplishment. But we should not be satisfied with reflecting on the past.


We must continue this process of change if the VR program is to respond effectively to the new challenges of a dramatically changing economic, social, and political environment.

The 1994 Harris poll documents the clear need for VR services:

- 68 percent of working-age people with disabilities are unemployed.
- 60 percent of those individuals who rate their impairment as "slight" are working, in sharp contrast to only 8 percent of those with severe disabilities who are working.
- Wage levels for those with severe disabilities are well below those of

nondisabled workers, and many persons with disability live in poverty.

This enormous gap clearly documents the need to continue the efforts to make the VR program as effective, efficient and responsive as it can be.

Throughout these 75 years, the VR program has demonstrated the ability to keep pace with the everchanging and increasing demands to provide effective services to people with disabilities. Through our collective experience, training, and research, coupled with real dedication and personal commitment, the VR system has assisted more than 9 million people with disabilities in achieving a place of true integration in society. As we look to the future, there will of course be new challenges. I am confident that the VR system will continue to expand and evolve without wavering from its central purpose—assisting people with disabilities in training for and securing high quality competitive employment. 

## American Foundation for the Blind Announces New Public Service Announcement Campaign

Did you realize that the rate of blindness and severe visual impairment increases sharply with age? This is especially noteworthy now that the "Baby Boom" generation is going past 50. Moreover, one in nine Americans currently over age 65 is severely visually impaired, and that number is expected to double by the year 2030.

With this in mind, the American Foundation for the Blind (AFB) has announced the release of a new public service announcement (PSA) campaign, entitled "We Help Those Who Don't See Well, Live Like Those Who Do." Its goal is to encourage older visually impaired individuals to take advantage of the many programs, services, and products available to help them remain independent and productive. Through these public service messages, it is hoped that older individuals and their adult children will recognize that losing one's vision does not mean losing one's way of life.

The campaign—in television, radio, and print—consists of two public service announcements (PSA's), "Self-Reliant" and "Family." The messages depict before-and-after scenarios that show how, with some guidance, information, and training, individuals with visual impairments can continue to do the things that are dear to them. According to AFB President Carl R. Augusto, "There are nearly 5 million Americans who are blind or severely visually impaired, and many are not receiving the readily available services they need. AFB provides free information and referral to find those services around the country."

"Self-Reliant" features an older woman who, with the use of visual aids, is able to continue cooking for herself and an older man who, by turning to a local agency, learns that his vision loss does not mean isolation and confinement. "Family" portrays an older couple who can resume their treasured card games after they acquire large-print cards and a grandfather who regains the confidence to take his granddaughter for weekend outings, thanks to his low vision aids.

The campaign was developed with the Seattle-based creative agency Planet Earth Foundation (PEF) using older visually impaired people contacted through Seattle's Community Services for the Blind and Partially Sighted. AFB is currently distributing the PSA's to media outlets in all 50 states and—for the first time—in partnership with local blindness organizations and agencies in select markets.

For more information on the "We Help Those Who Don't See Well, Live Like Those Who Do" public service announcement campaign, contact Liz Greco, Vice President, Communications, American Foundation for the Blind, 11 Penn Plaza, Suite 300, New York, NY 10001; Telephone: (212) 502-7614; FAX: (212) 502-7770; E-mail: lgreco@afb.org.



# Vocational Rehabilitation: The First 50 Years<sup>1</sup>

Seventy-six years ago, when it all began, not everyone thought the vocational rehabilitation bill was a good idea.

"This bill," thundered Senator Lawrence Y. Sherman of Illinois, "... is a misdirected measure of charity. It is... an effort of scintillating decay. It marks the decadence of social institutions...."

It was 1919 and the emotions and uncertainties of the First World War were still felt across the land. The beginnings of a more realistic concern for the individual were there, surrounded by many things... fears of postwar unemployment, a Russian Communist revolution that was only 2 years old, the inevitable clashes of values between the rugged frontier code and the practical demands of an increasingly industrial society.

Senator Sherman was not entirely opposed to the idea, just to the bill. He was in favor of rehabilitating those who were of "industrious habits" but he wanted to make very sure that no disabled "vagrant" and no "odoriferous knight of the tomato can" would be included.

It had been nearly a year since Congressman William B. Bankhead of Alabama introduced the first bill and was joined promptly by Senator Hoke Smith of Georgia. The bill could scarcely be described as a response to a public demand; the newspapers had ignored it and the "spokesmen for the disabled" were a tiny, seldom-understood group.

It is not easy to clothe the events and the central figures with the garments of circumstance that surrounded them. The moral and social climate was largely shaped by the harsh realities of a highly competitive existence not only for the settler in the West but for the farmer and the city dweller. In the East,

where the concepts, plans, and programs for rehabilitation mainly were born, floods of immigrants had flocked to the coastal and other cities to try their fortunes under the Horatio Alger idea, a chance to go as far in life as their strength, initiative, and labor would take them, in competition with all others around them. Denied this in the "old country," they saw this American dream as an open door to the promised land. For some, it was. For others it was the sweatshop, a pick handle, or the almshouse.

In such an atmosphere and environment, to propose that people should spend their money, private and public, to bring persons with disabilities into the employment market—there to compete against their benefactors—required a rare blend of insight and courage. Only a few had it.

Outside the Congress, the men and the motives were diverse. Philanthropist Jeremiah Milbank already had established a "first" with the opening of the Red Cross Institute for Crippled and Disabled Men in New York City in 1917; he followed this up by sending the Institute's first director, Douglas C. McMurtrie, to Washington frequently to testify before Congressional committees and become a highly effective spokesman for people with disabilities and for rehabilitation programs.

The new veterans organizations, infused with the strength of thousands of members following World War I, were in favor of vocational rehabilitation for civilians, as long as it did not interfere with their objective of securing a separate program for veterans of World War I.

Dr. Charles A. Prosser, Director of the Federal Board of Vocational Education—where the program would be

supervised if enacted into law—was agreeable to such a special vocational rehabilitation program for the persons with disabilities, seeing it as a slightly specialized form of vocational education. Since the board already administered the Smith-Hughes (vocational education) Act and the vocational rehabilitation program for disabled veterans of World War I, it seemed reasonable to place such obviously related activities under the supervision of the same board. (It could not be foreseen at that time that the board's responsibilities for disabled veterans would not remain with the board very long.)

Although the Bankhead bill in the House and the Smith bill in the Senate were reported favorably by their committees, the 65th Congress adjourned without passing either bill.

When the new 66th Congress convened in 1919, Congressman Bankhead and Senator Smith reintroduced their bills and, under the forceful drive of Senator Smith, the bill passed the Senate despite objections from Senator Sherman and a handful of others.

In the House, a new Chairman of the Committee on Education, Congressman Simeon D. Fess of Ohio, chose to make some revisions in the bill and report his own measure. Thus, the new bipartisan "team" became Smith and Fess—and it is doubtful if two more diametrically different personalities ever joined in a common cause.

Democrat Senator Hoke Smith—a towering figure, a lawyer, newspaper owner and editor, former Cabinet member, former Governor of Georgia, and an unpredictable mixture of the conservative and the liberal—wielded a mighty influence wherever he spoke, including the Senate floor. If Hoke



Smith wanted a vocational rehabilitation bill, he probably would get it.

Republican Congressman (later Senator) Simeon D. Fess—product of an Ohio farm, former American history professor, dean of a college of law, university president, editor and writer—was the scholarly self-made man from the Midwest, bringing with him the mixture of moral values and conservative convictions of his background.

## The Smith-Fess Act

When the Fess bill reached the House floor, it encountered some stormy weather. Among other things, the Federal Board for Vocational Education was beginning to come under fire for its administration of the vocational rehabilitation program for veterans; some members of Congress doubted whether the board should be given any additional responsibilities until the ques-

***When the Fess bill reached the House floor, it encountered some stormy weather.***

tion of veterans services was resolved. Others felt that the bill invaded states rights, always a touchy issue, and still others termed it socialistic or worse.

Despite such opposition, the Fess bill was passed in October 1919 and sent to the Senate. It was April 1920 before the Senate passed the revised bill, adding an amendment that it had insisted upon the year before. This the House accepted and sent the measures to the White House, where President Woodrow Wilson signed it on June 2, 1920, as Public Law 236, 66th Congress.

Looking back, it is at once incredible and understandable that the enactment

of that first law was so widely ignored, which it was.

Incredible because it marked the first time that the national government had said, without justification on patriotic grounds, that public funds should be spent to help people with disabilities rise above their disabilities. Incredible because the industrial development of the country and the emergence of the labor movement was resulting in widespread adoption of state workmen's compensation programs to provide monetary relief for the industrially injured—and thereby had spotlighted the extent of the problem—yet so few people saw vocational rehabilitation in relation to these shattered lives.

Understandable because Congress and most people had other things on their minds. The newspapers, which uniformly passed over any mention of the passage or signing of the bill (except for the *Washington Post's* routine listing of bills signed), had more pressing business to report: the slaying of Mexican President Don Venustiano Carranza by his own soldiers; a new retirement law for federal civil service workers; AFL President Samuel Gompers' charges that Congress had done nothing to control the high cost of living; and whether opera star Geraldine Farrar's back was too bare.

Understandable because looking below the surface of human misery has not been a favorite preoccupation of large numbers of people. More than 25 [50] years ago Dr. John Culbert Faries—then retired from the directorship of the Institute for the Crippled and Disabled in New York City which he had served for many years—said in his history of the Institute: "It sometimes requires a social earthquake to cast up from dark and slimy depths into the light of day ancient wrongs and injustices which have long festered in the world. It took a bloody war to settle in this country, once and for all, the question of human slavery. It took another war to awaken society to its duty toward the person who suffers a physical handicap, whether it be congenital or the result of war, accident, or disease."

However, the proponents were convinced that people would become interested, that a start must be made, and that people with disabilities themselves, performing well on the job, would be their own best missionaries to the nation and to the world.

So with a new law, an authorization of \$750,000 for 1921 and an uncertain place in the Federal Board for Vocational Education, they began.

There was encouragement in the fact that several states already had passed some type of vocational rehabilitation law. A program was organized in some of these states and the remainder were trying to launch programs under their recent laws. In California, the constitutionality of a state law for rehabilitating workmen's compensation cases was ruled invalid by the court.

As a small federal staff was acquired slowly, the broad form of a state-federal vocational rehabilitation program began to take shape. The federal staff, from the outset, called regularly upon the experience of the state leaders, as program flesh was added to the skeletal structure of the federal law.

With surprising speed the first bulletin on vocational rehabilitation was issued to the states 3 months after the federal law was passed. It provided the basic concepts, policy guidelines, and many specific clarifications to help and encourage the states.

By early spring 1921, the federal staff had grown to six people. Included were figures like John A. Kratz, Tracy Copp, Frank J. Clayton, and Frederic G. Elton, whose names and careers were to become synonymous with the development of vocational rehabilitation in the United States, along with the other early figures, Lewis H. Carris and Frank Harrison.

These men and the small group of state directors had a task requiring an endless store of administrative skill, program insight, diplomacy, determination, and willingness to take a calculated risk. They faced some prodigious obstacles:

- a federal law which made no provision for medical help to remove or reduce the disability, or to pay the living ex-



penses of the handicapped client while he was being rehabilitated, or to serve the blind, the mentally ill, or the retarded;

- state departments of education which usually were not particularly interested in their own vocational education programs and even less in the newest member of the family, vocational rehabilitation;

- a feeling among many people that vocational rehabilitation, located in the education hierarchy, was an insidious form of federal aid to education, and therefore suspect.

But there always were a few people in all situations who could see beyond these reservations and doubts, who could see in an organized program of vocational rehabilitation a new promise for far better lives for the Nation's citizens with disabilities.

As the work moved into the mid-1920's and beyond, new leaders were emerging—people like Oscar M. Sullivan of Minnesota, W.F. Faulkes of Wisconsin, R.C. "Tommy" Thompson of Georgia, South Carolina, and Maryland (who had the distinction of initiating two of those state programs), T.C. "Terry" Foster of Alabama who, along with Homer L. Stanton of North Carolina, was later to join the Federal Office of Vocational Rehabilitation. Also working closely with "the Chief," John Kratz, were figures like S.S. Riddle of Pennsylvania, Marlow Perrin of Ohio, R.L. Bynum of Virginia, R.M. Little of New York, J.R. Jewell of Nebraska, Joseph D. Spitz of New Jersey, and Sam Woods of Mississippi.

In 1921, the first year of the new program, 523 handicapped people were rehabilitated into employment. In the following year, this number rose to almost 1,900; in 1923, the third year, the total reached more than 4,500.

A pattern of growth had been set. But the federal and state leaders knew (and lived daily with the fact) that their "noble experiment," so far, was just that.

By the mid-1930's, the vocational rehabilitation program had miraculously survived a series of legislative crises, the Wall Street Crash of 1929, the onset of the Great Depression, and the thrash-

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ing about of federal agencies as a new President set his New Deal in motion.

The miracle included not only survival but progress; and while a divine hand may have managed the survival, some very human hands were at work on the progress.

The constant threat was the temporary nature of the federal law. The 1920 act had provided authority for only 4 years. It was to be the young program's fate to scramble almost constantly for renewal of its legislative life for many years. During one such episode, a momentary oversight gave it a longer extension than it expected.

A bill to extend the program was being debated on the Senate floor in 1924, with Mr. Fess, now a Senator, in charge of the bill, and one of the foes of the original bill, Senator King of Utah, arguing that the proposed 4-year extension be cut back to 2 years.

Reminiscing in 1970, John Kratz described what happened on the Senate floor:

"The bill read that it was 'hereby authorized to be appropriated for the fiscal year 1925 and annually thereafter for a period of 3 years, the sum of \$1 million granted to the States.'... So Fess said to King, 'Well, how do you want to change this bill, if you're going to limit it? We'll go along with it. Come up here and write down what you want to write.' And Senator King wrote after the year 1925, 'year 1926 and 1927'—and didn't take out 'and annually thereafter for a period of 3 years'—so we got it for 6 years, instead of 4."

So with another lease on life, the program moved ahead once more. Some of

the federal staff were changing, with Fred Elton moving to the New York program and career names like H.B. "Doc" Cummings moving into the picture with Mr. Kratz.

As the 1920's gave way to the early 1930's, another important factor was entering the scene—a national association for the dedicated people who were holding together and building the vocational rehabilitation program. It had become apparent very early to the rehabilitation leaders that they would not find a satisfactory professional home in the only existing organization to which they had normal access, the National Society for Vocational Education. Itself beset by all manner of problems in the struggling field of vocational education, the society showed no prospect of providing the sort of organizational vehicle that its vocational rehabilitation brethren sought.

## **The National Rehabilitation Association**

Following several organizational efforts and changes of name, the National Rehabilitation Association came into being, first as the National Civilian Rehabilitation Conference (NCRC) in 1924, with W.F. Faulkes as Chairman, and in 1927 as the National Rehabilitation Association (NRA), when Marlow Perrin assumed the Presidency. (D.M. Blankenship, state supervisor in Virginia, had been in charge of the first gathering of the NCRC in 1924, serving in the capacity of Presiding Officer.) Around the NRA the vocational rehabilitation forces built a network of planning services, communications arrangements, legislative forces, and promotional activities. Professional improvements were urged, increased funds were sought at both state and federal levels, and ties with other public and private agencies were encouraged.

Out of the agonies of the early Depression years had come a rising demand to put some kind of floor under the economic hazards of the average worker. Many proposals were made and the arguments and the acrimony heightened as the time of decision grew closer. Beyond the temporary federal



programs like the WPA, the time for some permanent measures was at hand.

## The Social Security Act

One came in the Social Security Act signed by President Franklin D. Roosevelt on August 14, 1935. For most people, "Social Security" came to be synonymous with an income for retired workers. It also meant a greater protection from job layoffs through unemployment compensation, a public employment service to help both unemployed workers and employers, and federal funds to help pay the costs of state and local welfare programs for various categories of poor people.

For the vocational rehabilitation program, it also meant something else. The act gave the program, for the first time, a "permanent" authority in law. No longer did the administrators and the state directors have to live under the anxieties of a temporary authorization from Congress. Now they could plan with more confidence; now they could deal with state boards, governors, and legislatures with more assurance, especially since the Social Security Act also had raised the ceiling on the federal appropriation to nearly \$2 million—almost double what it had been before.

## The Program Moves Ahead

There was to be a curious repetition of history 30 years after the experience of the first Social Security Act: The 1935 Act probably stirred as great a storm of controversy as the Roosevelt administration had faced and, in the furor, few people paid attention to the provisions which were so important to vocational rehabilitation. In 1965, the Congress and much of the nation experienced another major policy debate over the 1965 amendments to the Social Security Act—centered around Medicare—and in the turmoil, little attention was paid to the fact that the new law included, for the first time, authority to use Social Security trust funds to pay the costs of rehabilitating disabled workers covered under the system.

As usual, the successful effort to secure the inclusion of vocational rehabilitation in the Social Security Act of 1935 had been spearheaded by a group of state directors, led by Mark Walter, Director of the Pennsylvania Bureau of Rehabilitation. His acumen and energy were to play decisive roles in rehabilitation legislation for many more years.

*The absence from the federal act of any clear provision for assisting blind persons through vocational rehabilitation was a source of disappointment and dissatisfaction to all concerned.*

He and "the Chief" [John Kratz] had wasted little time in personally getting the vocational rehabilitation program before the new administration. In 1933 they proposed to Harry Hopkins, the President's top assistant, what probably was the first organized proposal for rehabilitating public welfare cases: They proposed a special appropriation of approximately \$70,000 monthly for two years (1934 and 1935) solely for grants to the states to provide vocational rehabilitation services to public assistance cases. Hopkins agreed, the President supported it, and they got it, through a transfer of funds from the Federal Emergency Relief Administration.

Perhaps most important, the main objective of all this federal-state activity—the vocational rehabilitation of disabled people and their restoration to employment and useful places in life—was being accomplished on an increasing scale. From the 523 rehabilitated in 1921, the figures had risen to a total of 9,422 in 1935 and continued this upward trend to 11,890 by 1940.

Back of this was an equally steady increase in the willingness of the Federal Government and the states to provide more funds for this work. Following the increase in appropriation authorizations in the 1935 Social Security Act, the federal funds rose from \$1 million in 1935 to \$1.9 million in 1940. State funds grew from \$1.2 million in 1935 to \$2.1 million in 1940. For those who had labored since the early days—for people like Irwin M. Ristine of the federal staff, Harry Hicker of California, Claud Andrews of Florida, Willis W. Grant of Iowa, John Lasher of Wisconsin, Homer W. Nichols of Kentucky, H.C. Corpening of North Carolina, Leif Fredericks of Montana, Maurice I. Tynan of the State Agency for the Blind in Minnesota, and many others—this growth was tangible evidence that their concepts and convictions had been right, and that their methods were bringing results.

The absence from the federal act of any clear provision for assisting blind persons through vocational rehabilitation was a source of disappointment and dissatisfaction to all concerned. Fortunately, the history of work for people in the United States who were blind had been such that many state agencies, along with the outstanding voluntary organizations such as the American Foundation for the Blind and others, had helped to keep the problems, needs, and abilities of people who were blind reasonably well in focus.

## The Randolph-Sheppard Act

During that period, the Congress took two steps which were to have lasting benefit for the nation's citizens who were blind. A young Congressman from West Virginia, Jennings Randolph, teamed with Senator Sheppard to secure enactment in 1936 of the Randolph-Sheppard Act authorizing the Federal Government to license blind persons to operate vending stands in federal buildings (and subsequently on other federal property). Most of the states made similar provisions for "blind stands" on state property, with the result that the operation of these vending stands today represents a mul-



timillion dollar business employing thousands of people who are blind and their sighted assistants. In 1938, Congress passed the Wagner-O'Day Act, which set up a special arrangement in which the Federal Government makes certain of its purchases from workshops for the blind, through a national Committee on Blind-Made Products, a committee which still functions successfully today.

In 1940, the "Kelley hearings," conducted by Congressman Augustine Kelley of Pennsylvania, reflected another strong effort to broaden the law. Though not successful at the time, "Gus" Kelley's hearings accomplished two important things: They kept the issue very much alive and they produced an impressive amount of data and documentation regarding the need.

The climb out of the Great Depression in the late 1930's was a time of mixed feelings, of hope and anxiety. Along with the revival of confidence and the preliminary signs of prosperity were disquieting events. Most ominous of all were the war clouds hanging over Europe, and the conviction of many that those clouds would soon drift across the Atlantic and release their storm on the United States.

## World War II

Congress debated with great heat the need for preparedness versus the need to stay out of other peoples' wars. The Billy Mitchell battle for an Air Force was waged all over again. By 1940, the Congress was ready to adopt a military draft. By the end of 1941, the need for it became shockingly clear: Pearl Harbor and World War II.

Like other government programs, the rehabilitation agency moved into emergency war planning at once. Everywhere one turned, one question immediately presented itself: Where will the manpower come from? With the draft steadily depleting the supply of young workers, new sources had to be found for industry and all the other supporting services.

Vocational rehabilitation, a producer of trained manpower, could help and,

in these circumstances, war planners grasped this elemental fact. Mr. Kratz and his colleagues made this point effectively, with the result that the program not only received valuable support from new sources but was given an essential classification under manpower controls so that state agencies would not lose their professional staffs on whom the whole rehabilitation effort depended.

Employers who had not been enthusiastic about hiring persons with disabilities were having second thoughts now, and some were seeking out workers with disabilities. Placement problems eased, particularly as industry began to break its operations down into

*Employers who had not been enthusiastic about hiring persons with disabilities were having second thoughts now, and some were seeking out workers with disabilities.*

simpler job components which could be done with less training, less strength, and less versatility. But other problems increased—disruptions of schools and other training facilities, transportation difficulties, and many others.

But most of all, in the face of war needs, the inadequacy of the federal law had become a serious matter. These impediments of more than two decades—lack of medical, surgical, and hospital services, lack of maintenance of disabled clients, lack of provision for the blind, the mentally ill, and the retarded—as well as problems involved in the basic federal-state financing system itself—had to be eliminated if this program were to make its contribution to the war effort.

The legislative process began in 1942. During one session with Congressman Larabee of Indiana, Chairman of the

House Committee on Education, Mr. Kratz and Mr. Walter found him adamant in refusing to handle the bill until they pointed out that it would include provision for disabled veterans as well as civilians. This changed the situation promptly for Mr. Larabee and he instructed the two to meet with committee member Graham Barden of North Carolina and "tell him I want him to take care of it."

It was not quite that easy for Mr. Kratz and Mr. Walter and their coworkers in NRA. Congressman Barden had a mind of his own and ideas of his own. Mr. Walter found the way eased a bit when he and Mr. Barden discovered that they were members of the same college fraternity.

One issue—whether the state-federal program would serve veterans—was solved for them before the Barden bill ever came out of committee. In March 1943, the Congress passed a bill providing for rehabilitation of veterans through the Veterans Bureau—and that settled that.

In the Senate, the amendments to the VR Act had been introduced by Senator Robert M. LaFollette of Wisconsin and under his guidance the bill moved through the committee without great delay.

In May 1943, the House passed the bill and the Senate followed suit in June, with the latter-stage assistance of Senator Robert Taft of Ohio. The Senate-House conferees adjusted their differences later that month and on July 6, 1943, the Barden-LaFollette Act was signed into law as Public Law 113, 78th Congress.

Now the stage was set, both for a far more effective war effort by the rehabilitation workers and for a vastly improved long-range service to the nation. And the third major event in the life of this program for people was now history.

The Federal Security Agency had been formed, bringing together the government's major programs in health, education, social security, welfare, and rehabilitation. Within it, the Office of Vocational Rehabilitation (OVR) was established in 1943, providing the sort of autonomous unit of government that rehabilitation leaders had sought for



so long. Michael J. Shortley was appointed the first Director of OVR, a post he held successfully into the beginning of the next decade.

In the military services, a medical officer with the Army Air Corps named Major Howard A. Rusk was working with sick and injured patients in the hospital at Jefferson Barracks, Missouri. He organized a convalescent rehabilitation program for soldier-patients on the mend. It worked. Soon the Army Air Corps was organizing the program in all its hospitals. The Army and the Navy organized reconditioning and rehabilitation programs. Groups of military officers were sent to the Institute for the Crippled and Disabled in New York City for "crash" training programs in rehabilitation. Anticipating the end of the war, discussions were held on the need for inhospital rehabilitation programs for disabled veterans to function in coordination with the vocational rehabilitation and education program of the Veterans Bureau.

When the end of World War II finally came, the nation had one thing to be grateful for, out of all the immense tragedy that the war had heaped upon a people: It was far better prepared to rescue and restore its disabled citizens, veterans, and nonveterans alike, than at any time in its history. If, as Dr. Faries said of World War I, it took a war to awaken society to its duty toward the person who suffers a physical handicap, it seemingly took World War II to convert this sense of duty into broad-scale action.

Whether anyone realized it or not, the "rehabilitation movement" was getting ready for the 1950s. As the war years receded and a new decade approached, the state-federal program was being joined by many other people and programs who shared their conviction that rehabilitation programs for people with disabilities must now emerge from the demonstration stage and begin to confront the whole massive problem of disability among the American people.

For this task, Mr. Shortley was surrounded by some outstanding people in his Office of Vocational Rehabilita-

tion. From the Minnesota rehabilitation program, Donald H. Dabelstein had come to OVR in 1943 and, in a very few years, had become the agency's creative program thinker, its conscience, and its completely devoted servant. Guiding the administration, fiscal and relationship phases of the work was Joseph Hunt, trained in management and an alumnus of the early days of the Social Security Board. Among the group was one of the earliest professional proponents of expanded vocational rehabilitation services for the mentally retarded, Dr. Salvatore DiMichael, psychologist and innovator. Guiding the crucially important early days of the new medical programming in vocational rehabilitation—a field largely foreign to many state rehabilitation agencies—was Dr. Jack Masur, later to have a distinguished professional career as director of the clinical center at the National Institutes of Health.

There was great motion in rehabilitation outside the public program. Dr. Rusk took his wartime experience and his plans to New York City, there to found the famous Institute of Rehabilitation Medicine at New York University Medical Center. From Rochester, Minnesota, Dr. Frank H. Krusen, long a leading figure in the field of physical medicine, extended his influence out from his home base at the Mayo Clinic to preach the gospel of rehabilitation to a wider audience. In other medical specialty fields, more and more physicians began to evince an active interest in rehabilitation for their patients.

In the Department of Medicine and Surgery of the new Veterans Administration, under General Omar Bradley, General Paul R. Hawley, and Dr. Paul B. Magnuson, the drastic overhauling of the whole system of veterans' medical care included specific plans for a comprehensive rehabilitation service for hospitalized veterans.

These several changes on the medical scene produced numerous specific results. One was the establishment of the Baruch Committee on Physical Medicine, by Mr. Bernard Baruch, financier-philanthropist, to honor the memory

of his physician-father, Dr. Simon Baruch. The committee accomplished numerous things: the training of increased numbers of young physicians in the physical medicine specialty, plans and blueprints for new styles of rehabilitation facilities, and general emphasis upon restorative care throughout the medical profession. Another result was the formation of a new medical specialty board—the American Board of Physical Medicine and Rehabilitation. Now, for the first time, medicine had a fully accredited professional body of physicians to concentrate their attention upon medical and related restorative work for the nation's citizens with disabilities, and to further bolster the efforts of professional organizations like the American Congress of Physical Medicine and Rehabilitation (PM&R) and the related scientific body, the American Academy of PM&R.

### **The President's Committee on Employment of the Handicapped**

The spillover of postwar activity for disabled veterans into new activities for all people with disabilities took many forms. An example was the formation of the President's Committee on Employment of the Handicapped (later renamed the President's Committee on Employment for People with Disabilities), which grew primarily out of two things. One was the work of Paul Strachan, President of the American Federation of the Physically Handicapped, who was the prime mover in securing passage of a Congressional resolution to authorize a "National Employ the Physically Handicapped Week" (NEPH). The other was the Retraining and Reemployment Administration (under Marine General Graves B. Erskine), a temporary federal agency which was concerned with the coordination and strengthening of governmental programs for the readjustment and reintegration of veterans into civilian life. When it disbanded, Labor Secretary Louis B. Schwollenbach suggested formation of a President's Committee to carry on with NEPH Week, and President Harry Truman agreed.



The President's Committee on Employment of the Handicapped offered a working promotional forum in which all governmental and private organizations and individuals could join in a common goal of breaking down unrealistic barriers to the employment of people with disabilities. The committee, with William P. McCahill at the helm, was to have a series of distinguished chairmen, beginning with Admiral Ross T. McIntire. He was succeeded by Marine General and former Congressman Melvin J. Maas; by Harold Russell, past Commander of the Disabled American Veterans and Motion Picture Academy award winner.

With the rehabilitation movement expanding on so many fronts, the National Rehabilitation Association was growing with it. An editor for the association's *Journal of Rehabilitation* was hired shortly after the end of World War II and, by 1948, the Association hired its first full-time paid staff Director, E.B. Whitten, who continued in that role for 27 years.

While still struggling with the aftermath of World War II, the country found itself faced with a new conflict—the “police action” in Korea. Once again, the nation set in motion its preparedness machinery and the vocational rehabilitation program, like most others, prepared to help.

In late 1950, OVR came under the stewardship of its second director, Mary E. Switzer, to begin a long and distinguished career of leadership in the state-federal program of vocational rehabilitation.

The Korean War produced a problem that all wars create—a shortage of manpower. This was something the vocational rehabilitation program understood. It also was understood by President Truman and by the Director of the Office of Defense Mobilization, Arthur S. Flemming (later to be Secretary of Health, Education, and Welfare). Late in the spring of 1951, Mr. Flemming named a distinguished panel of people to serve as a Task Force on the Handicapped, to advise the Office of Defense Mobilization on the measures that should be taken to strengthen rehabilitation, training, and employment pro-

grams to make better use of people with disabilities in the mobilization effort. The task force, chaired by Dr. Theodore Klumpp, completed its work in early 1952 and submitted a report which was widely used in the general advancement of rehabilitation work for people with disabilities. More importantly, the report became a springboard for legislation that was to follow in 1954.



Mary E. Switzer

The 1952 election of Dwight D. Eisenhower as President brought to Washington the first political party change in 20 years. Along with a Republican President was a Congress controlled by the same party, so that substantial changes in government policies and programs could be expected.

One of the first actions taken by the new administration was to propose the creation of a Department of Health, Education, and Welfare, built upon the existing structure of the Federal Security Agency. With the support of Congress, and particularly with the personal involvement of Senator Robert Taft of Ohio, the department was approved and came into being in April 1953 with Mrs. Oveta Culp Hobby appointed as the first Secretary.

Immediately after creation of the department, work was begun on legislation to make some major amendments in the vocational rehabilitation law. As always, the state directors of vocational rehabilitation were brought into the

forefront of the planning and refining of a bill, through numerous meetings with Under Secretary Nelson Rockefeller, Miss Switzer, and Mr. Dabelstein. The need for legislation was quite apparent. The state-federal program had definitely begun to plateau. From a figure of 66,193 people with disabilities rehabilitated in 1951, the annual totals began to descend—to 63,632 in 1952, to 61,308 in 1953, to 55,825 in 1954. Hanging over this was a major and quite serious defect in the financing system of the existing law, creating a situation which grew more critical each year.

## The Fifties and Sixties

Hearings on rehabilitation legislation began in the House in 1953, before the new administration had time to prepare and present its own legislative proposals. However, Miss Switzer testified before the Education and Labor Committee, chaired by Congressman Samuel McConnell of Pennsylvania, and presented certain legislative needs which in major outline were to constitute the administration's later position. Many other witnesses appeared before the committee, including Mr. Whitten of NRA; Mr. Strachen of the American Federation of the Physically Handicapped; R. C. “Tommy” Thompson, State Director of Vocational Rehabilitation in Maryland; and numerous other leading figures.

In the new department, Secretary Oveta Culp Hobby and Under Secretary Nelson Rockefeller personally presented the rehabilitation legislation to President Eisenhower. Under Secretary Rockefeller went much further; he directed his staff to secure voluminous data, hold many meetings, and prepare numerous charts, assembling the data in most effective form and preparing for Congressional hearings.

He was an articulate and effective witness before the committees. The McConnell committee, after prolonged consideration of the several and often conflicting proposals before it, reported a bill which contained many features of the administration proposals plus sections reflecting other views.



In 1954, the Senate Committee on Labor and Public Welfare, under Senator H. Alexander Smith of New Jersey, got down to serious work on the rehabilitation bill. Its Health Subcommittee, chaired by Senator William Purtell of Connecticut, reported a bill which reflected nearly all of the administration's legislative proposals, with a few refinements and clarifications.

***Of all the changes wrought by the 1954 amendments, the most fundamental was to change the public program from a single grant system to a multiprogram approach to disability and rehabilitation.***

## **The Vocational Rehabilitation Amendments of 1954**

Out of the Senate-House conference on the bill came the fourth milestone in the legislative history of the public rehabilitation program—the Vocational Rehabilitation Amendments of 1954, signed by President Eisenhower on August 3, 1954, as Public Law 565, 83d Congress.

Of all the changes wrought by the 1954 amendments, the most fundamental was to change the public program from a single grant system to a multiprogram approach to disability and rehabilitation. Now, in addition to the basic program of grants to states for providing vocational rehabilitation services to disabled people, there would be a separate system of grants for research in rehabilitation, another for

training rehabilitation personnel, another for helping the states to extend and improve their programs of service, another for projects to help both public and private organizations expand their rehabilitation services.

There were other important improvements. . . the broadening of the Randolph-Sheppard Act . . . the use of basic grant funds to improve and expand rehabilitation facilities . . . and a new system of financing the basic grants-to-states program, ending the financial crisis that hovered over the program.

Legislatively, 1954 was truly a rehabilitation year. The Hill-Burton Act for constructing hospitals was amended to authorize a special appropriation to help build rehabilitation facilities, primarily those of a medical nature. The Social Security Act was amended to protect the insurance benefits of covered workers who became disabled. To carry out the examination of these disability "freeze" applications for the Social Security Administration (SSA), most states designated the state vocational rehabilitation (VR) agencies, so that a working partnership was established with SSA, along with a stress on rehabilitating these men and women.

No facet of rehabilitation development in the 1950s was more remarkable than in rehabilitation facilities. Across the country were institutions which had pioneered for many years—facilities like the Industrial Home for the Blind in Brooklyn, where one of the nation's outstanding leaders in work for the blind and the deaf-blind, Peter Salmon, had blazed many of the trails that marked 20th century progress in preparing blind people to work successfully. . . like the Curative Workshop of Milwaukee, which had been the inspiration for many early leaders in vocational rehabilitation. . . like the Institute for the Crippled and Disabled in New York City. . . like the chain of Goodwill Industries workshops. . . like the outstanding Jewish Vocational Service in Chicago. . . like Dr. Frank Krusen's Department of Physical Medicine at the Mayo Clinic.

But now, in the 1950's, the pioneering stage began to give way to the devel-

opmental stage. In Virginia, the state vocational rehabilitation (VR) agency had taken over a large Army hospital and established the first comprehensive state-operated vocational rehabilitation center at Fishersville. In New York, Dr. Rusk's Rehabilitation Institute moved from temporary quarters into a new and permanent facility. Dr. Paul Magnuson left Washington, DC, to return to his native Chicago and founded the Rehabilitation Institute of Chicago. In New Jersey, Dr. Henry Kessler, who had influenced the whole course of vocational rehabilitation in the twenties and particularly its strong involvement with workmen's compensation, had opened the Kessler Institute of Rehabilitation in West Orange. In the Office of Vocational Rehabilitation in Washington, DC, the facility movement was guided, exhorted, and prodded by Henry Redkey and backed up by William Page and a handful of others. A Conference of Rehabilitation Centers was formed, later to become the Association of Rehabilitation Centers, and still later to join with the National Association of Sheltered Workshops and Homebound Programs in 1969 to found the International Association of Rehabilitation Facilities.

It is doubtful that anyone will ever adequately portray the sort of growth that took place in rehabilitation in the 1960's. It took so many forms, old and new, and each form multiplied. State VR agencies not only grew in numbers of disabled people rehabilitated, in funds and in staff; they also moved into special programming to conduct demonstration projects, provide for more and better staff training, and organize special programs for disability groups (e.g., for people who are deaf, those who are mentally retarded, persons with epilepsy, and others). Some agencies developed their own VR centers; nearly all worked out new arrangements for more regular and intensive use of voluntary centers and workshops.

Rehabilitation programs in the 1960's were to make their way forward in a new social climate, where opportunity and obstacle often walked side by side. It was to be a decade marked by glori-



ous accomplishments and bitter frustrations, a decade of scientific miracles, explosive riots, a man on the moon, a divisive war, heart transplants, and environmental pollution.

The rehabilitation programs, now firmly established, would have to be equal to this climate. They had grown in size and social influence because they had responded to the communities in which they functioned and to the times in which they served. So they welcomed the 1960s.

The rehabilitation research program, set in motion by the 1954 amendments, was now in full operation, helping to support a vast variety of experiments, analyses, and demonstrations, in pursuit of new knowledge and better methods for restoring people with disabilities to activity and usefulness. To the program's official review body, the National Advisory Council on Vocational Rehabilitation, had come a parade of the nation's foremost people in rehabilitation, education, medicine, labor, and industry. Early in the decade, the first in a series of Rehabilitation Research and Training Centers was supported through the research program, assuring a number of "places of excellence" in which the expertise of a topflight center was combined with the resources of a university to assure maximum results in research, professional training, and care of persons with disabilities. Through an extension of the rehabilitation law plus the 1960 "Health for Peace" Act, a program of international rehabilitation research was developed.

The training program had reached out to universities and colleges throughout the United States, offering them a way to help in this national approach to disability. The nation needed thousands of new, trained professional people to man these expanding programs. The universities responded, and in the process widened the circle of rehabilitation influence tremendously.

Other research was to play a vital role in the battle to prevent and overcome disabilities. With development of the polio vaccines, this calamitous disease would virtually disappear from the American scene. The vast research

program of the National Institutes of Health and the comprehensive health programs of the Public Health Service were constantly giving medical science new tools to work with in combatting disease and disability. The National Society for Crippled Children and Adults had formed its Easter Seal Research Foundation and entered into cooperative support of research projects on a wide front in disability.

The educational field was affected by more than the rehabilitation training program, by far. Beginning with the National Defense Education Act, the Congress increasingly demonstrated its willingness to give the U.S. Office of Education (OE) greater resources to work with in strengthening the nation's educational system at all levels. Both through general educational support programs, such as the Elementary and Secondary Education Act, and through special laws for the education of handicapped children, youth, and adults, OE was able to eventually mount a large-scale program to produce the kind of teachers needed by the thousands to meet the unique educational needs of students with disabilities.

Other federal agencies with skills and resources for helping people with disabilities were growing too. The U.S. Employment Service and the state employment services, which for so many years had played a prominent role in selective placement and in many cooperative efforts with the federal and state organizations in rehabilitation, now were expanding and helping to open up new job markets. The U.S. Civil Service Commission, already known for its pioneering in fitting disabled people into a great variety of federal positions, was getting ready to look at its procedures all over again to give more applicants with disabilities a chance to perform.

The election of John F. Kennedy as President of the United States in 1960 gave promise of many things, and those concerned with people with disabilities could anticipate a new level of activity on behalf of those who needed help. One resounding step was taken very soon in the new administration: The

President and the Kennedy family took the lid off the dark subject of mental retardation, asking the nation to face the problem openly and join in a concerted program to create better lives for children and adults with mentally retardation. With great vigor, President Johnson and particularly Vice President and Mrs. Humphrey pressed forward later with the campaign, to produce probably the greatest breakthroughs in mental retardation ever seen in one decade.

An effort was made in 1961 to secure passage of new rehabilitation legislation, without success. The process was repeated annually for the next 3 years with the same result. But momentum for major changes in the law was building up as the need became more apparent to both state and private rehabilitation agencies and groups. Congresswoman Edith Green of Oregon and her Special Subcommittee on Education wanted a bill which would include a new approach to the financing system for the basic state-federal program. One result was that the Vocational Rehabilitation Administration (OVR underwent an organizational and name change in January, 1963) prepared a marathon series of tables showing what would happen to the states under various methods of calculating allotments and grants. When one financing system finally passed the acid test of "the tables," moving the rest of the bill proved fairly easy.

On the other side of Capitol Hill, one of the great congressional champions of health and rehabilitation programs, Senator Lister Hill of Alabama, would handle the bill. As author of the Hill-Burton Act and formula and other major pieces of legislation, including creation of the National Institutes of Health, he could be expected to have some ideas of his own on advancing the rehabilitation programs. As Chairman of the Senate Committee on Labor and Public Welfare, he sat atop not only the department's health legislation but its education programs and a host of other activities. As Chairman of the Senate Subcommittee on Appropriations for the Departments of Labor and Health, Education, and Welfare, he was



a powerful figure in determining annual budgets to carry out the laws that had come before his other committee.

Leading the minority side of the subcommittee, Senator Norris Cotton of New Hampshire, veteran of 30 years as a state and national legislator, usually put his vast skills behind the rehabilitation programs.

On appropriation matters, Senator Hill usually saw things about the same way as his counterpart in the other body, Congressman John Fogarty of Rhode Island, Chairman of the House Appropriations Subcommittee for the two departments. Mr. Fogarty, an aggressive advocate of advancing health and rehabilitation programs, was to fashion a remarkable career in Congress before his tragically sudden death 2 hours before a new Congress convened in January 1967. His committee usually functioned with more harmony than some because of the rapport between Mr. Fogarty and the ranking minority member, Congressman Melvin R. Laird of Wisconsin, a consistent supporter of the rehabilitation programs, author of the popular "Laird Amendment" to the Vocational Rehabilitation Act, and later to become Secretary of Defense.

In 1963, there was a time when everything else stopped while a stunned nation reacted to the assassination of President Kennedy. Before the decade ended, two more great national figures, Dr. Martin Luther King and Senator Robert F. Kennedy, were to die in the same senseless fashion.

The nation surmounted these tragedies, as it has so many times before, and a new President assumed the burdens of high office. In his January 1965 Health Message to Congress, President Johnson urged rehabilitation legislation and in March sent the administration bill to Congress. By the time the House Education and Labor Committee had reported a vocational rehabilitation bill in May 1965, the legislative wheels were turning furiously throughout the health, education, and welfare spectrum. The Medicare issue was finally coming to a boil after more than 20 years, accompanied by a plan to phase out both the "vendor care" sys-

tem of medical care payments and the Kerr-Mills plan for providing health-care for the needy, to be replaced with a new system of healthcare grants to the states. In such an atmosphere the vocational rehabilitation amendments passed the House in late July.

Against this kind of competition for time and attention, the rehabilitation bill moved through the Senate, conference action, and final passage with remarkable speed. When President Johnson signed the bill on November 8, 1965, he had put his pen to the fourth monument marking the progress of one of the nation's fascinating success stories.

The new law provided a long list of improvements for the program... the construction of new rehabilitation facilities... grants to speed improvement of workshops for people with disabilities... a new method of allotting federal funds among the state VR agencies and a uniform federal share of 75 percent of the program costs... funding for statewide planning in rehabilitation in each state... elimination of economic need as a requirement for obtaining rehabilitation services... creation of a National Commission on Architectural Barriers... and other steps to expand and perfect programs.


There would be additional improvements made in the law in 1967 and 1968, including support for a new National Center for Deaf-Blind Youth and Adults, a special program for disabled migrants, additional provisions for help in constructing facilities, and a new grant system for evaluation and work adjustment.

But more than the law books were changing. In 1967, HEW Secretary John W. Gardner, Under Secretary Wilbur J. Cohen—long a friend of rehabilitation, a key figure in the 1965 amendments to the Act, and later to be Secretary—and Miss Switzer were the principal figures in a major organizational change in the department. A new agency, the Social and Rehabilitation Service, was created, designed to realign the service-giving agencies into a new approach to the problems of all disadvantaged people, with Miss Switzer as the first Administrator. It brought together the rehabilitation agency (redesignated as

the Rehabilitation Services Administration, or RSA), the welfare agency, the Children's Bureau, and the Administration on Aging. The welfare functions were reconstituted into two units, the Assistance Payments Administration (in charge of welfare payment activities) and the Medical Services Administration (in charge of Medicaid and related medical services).

Now the VR program faced a challenge of unprecedented size—of bringing to the problems of the poor and disadvantaged the concepts, the philosophies, and the methods on which VR had grown, without abating its concern for people with physical and mental disabilities.

With the inauguration of Richard M. Nixon as President of the United States in January 1969, another new chapter in the life of the public program of rehabilitation began. A new team assumed immense tasks in the Department of Health, Education, and Welfare under Secretary Robert H. Finch. Upon the retirement of Mary Switzer, John Twiname was named Administrator of the Social and Rehabilitation Service and Edward Newman succeeded Joseph Hunt to become the second commissioner of the Rehabilitation Services Administration to begin planning for the next decade of progress and for the second 50 years of one of the nation's oldest programs of service to people.

It is a time to look back with affection and admiration on a program which a House committee once described as "a monument to the growth of an idea." It is also time to look ahead into an exciting future. 

## Note

1. Reprinted (with some editing to reflect later developments) from: *50 Years of Vocational Rehabilitation in the U.S.A. 1920-1970*, Rehabilitation Services Administration, Social and Rehabilitative Service, U.S. Department of Health, Education, and Welfare: Washington, DC (1970).



## Motorola Offers New Additions to Line of Cellular Telephones for Hearing Impaired

Motorola recently introduced new cellular phone models that may be used in conjunction with a HATIS (Hearing Aid Telephone Interconnect System) device allowing many hearing impaired persons the ability to use a cellular telephone. The MicroTAC Lite II and MicroTAC Lite XL cellular phones, available from cellular service providers in most major markets across the country, are easy-to-use and affordable pocketable phones full of features such as HATIS compatibility.

"We're quite pleased to not only introduce these new phone models, but to also make them available to an audience who desires the ability and flexibility that millions of consumers have come to appreciate from cellular," said Suzette Steiger, corporate vice president and general manager, U.S. Markets Division, Motorola Pan American Cellular Subscriber Group. "Motorola has worked diligently to develop affordable phone models that will operate with the HATIS device and provide users the same level of quality they have come to expect from our entire product portfolio."

The MicroTAC Lite II and MicroTAC Lite XL phones, both with slim new eurostyle designs, come equipped with some of the most popular phone features of late. They include: three dedicated, one touch Turbo Dial™ keys for frequently dialed numbers; the VibraCall™ alert option, allowing users the ability to set their phones in a vibration alert mode for situations such as a restaurant or theater, where the sound of a ring may be inappropriate; data capability for laptop and faxing needs; internal rapid charging, eliminating the need for bulky chargers; headset jack for convenient, hands-free operation with optional headset; 99 alphanumeric memory locations to create a personal phone directory; and several security features to help protect against unauthorized use.

Last autumn, Motorola announced it had entered into an agreement with Phoenix Management of Fountain, Colorado, to modify several of its cellular telephone models for use with the company's HATIS device. When affixed to a Motorola phone, HATIS enables many hearing disabled persons to use a cellular telephone—some for the very first time.

"A unique, new application of the VibraCall alert option for people with hearing disabilities is the ability to 'feel' the phone ring while it's in your pocket or in your hand," said Jo Waldron of Phoenix Management. "For some, this feature is a great choice; for those of us who are deaf, VibraCall is the perfect solution."

Already announced HATIS-compatible models include the MicroTAC Elite™ personal cellular phone and several transportable phone models. The device, which operates when connected to the phone's audio interface, actually allows those who are hearing impaired or deaf, via their hearing aid with a coil, to make and receive cellular phone calls.

To operate with Motorola's just-announced MicroTAC Lite II or MicroTAC Elite personal phone models, users may contact Phoenix Management directly to purchase the HATIS device, which simply plugs into the headset jack on the phone. Those interested in purchasing one of the modified Motorola transportable cellular telephones (such as the Carry Phone model) should contact their local cellular service provider. Carriers can then work with Phoenix Management to fulfill customer requests.

HATIS Systems will work with cellular phones, two-way radios, landline-residential and office phones, cordless phones and pay phones with a retrofit, multimedia computers and laptops, CD video game systems, CD or cassette players, televisions, stereos, radios, Walkmans, television cameras, and more.

Phoenix Management, Inc., a Colorado Corporation, was started in 1988 by Jo Waldron and Shirley Crouch. They came up with the concept for HATIS systems, which is patent pending and in manufacturing status. Waldron who is deaf and Crouch who is hearing impaired, developed HATIS out of Waldron's frustration at not being able to use telephones, including cellular.

Waldron, the 1987 Disabled American for the Nation and member of the President's Committee on the Employment of People with Disabilities, states "One simply cannot understand the value of telecommunications, unless you can't use it."

For further press information, please contact: Motorola Cellular Subscriber Group, 600 North U.S. Highway #45, Room AN482, Libertyville, Illinois 60048. Telephone: (708) 523-2841. FAX: (708) 523-8770. For all other inquiries, please contact Motorola's Cellular Information Center at 1-800-331-6456.



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# NEW PUBLICATIONS AND FILMS

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## **Chronic Disease and Disability. A Contemporary Rehabilitation Approach to Medical Practice.**

*Ross M. Hays, M.D., George H. Kraft, M.D., and Walter C. Stolov, M.D. Demos Publications, Suite 201, 386 Park Avenue South, New York, NY 10016. 279 pages. Softcover, \$29.95.*

Intended to provide a brief basic foundation of information about chronic disease and disability, this book is designed to be used by health-care professionals who are being exposed to the concepts of chronic disease and disability for the first time. It provides the clinician with a basic understanding of the more common aspects of disability and the terminology used in rehabilitation. The first sections of this text describe general principles of assessment and treatment of the patient with disability. This is followed by descriptions of the commonly encountered disease syndromes that result in chronic impairment and by a discussion of the psychological and vocational aspects of disability management.

This book should be especially useful for medical students, as well as for those who practice medicine in an acute care context but need an introductory reference to the more common disabling conditions.

Over 14 percent of the adult population now suffers from chronic diseases and 70 percent of the population will suffer disability at some point in their lives.

## **Special Educational Needs.**

*Ronald Gulliford and Graham Upton, editors. Routledge, 29 West 35 Street, New York, NY 10001. 211 pages. Hardcover, \$69.95.*

The nature of provision for special educational needs in England has changed dramatically over the years following the Warnock Report and the 1981 Education Act, with an increased awareness of educational needs and a focus on improving the quality of provision for much larger numbers of children. This book underpins current practice by providing necessary and relevant information about the impairments and disabilities which may contribute to the development of handicap and may limit educational progress.

Against a context of a generic understanding of special education, the book stresses the entitlement for all children to a broad and balanced curriculum and explores ways in which the national curriculum can be adapted to meet the needs of children with various handicapping conditions. The central chapters focus on particular areas of special educational needs, each chapter being written by a specialist who explores in detail how conditions can be recognized, what specialist skills and resources are needed, and the implications for provision, teacher support, curricular access, assessment, and classroom management.

## **Standards of Work Performance. A Functional Assessment and Training Manual for Training People with Disabilities for Employment.**

*Vivienne C. Riches. Brookes Publishing Co., Inc., P.O. Box 10624, Baltimore, MD 21285-0624. 496 pages. Softcover, \$44.*

To succeed in today's competitive job market, individuals with developmental disabilities need to be skilled in more than just the basic job requirements.

A functional assessment and training manual for effectively preparing individuals with disabilities for employment, This book explores 10 specific categories where individuals with disabilities are likely to encounter problems in the workplace and offers creative strategies for improving performance in each of those areas: punctuality and attendance, dress and hygiene, reaction to supervision, getting along with coworkers, concentration and performance, workplace (organization), safety, behavior regulation, communication, and memory performance.

Working from the assessment forms and checklists included in this manual, a counselor can monitor and record critical information about an individual's work behaviors, routines, attitudes, and practices to determine the exact skills a person needs to sharpen—skills such as listening to instructions, ignoring distractions, seeking help when necessary, and responding appropriately to coworkers.

Vocational counselors, teachers, job coaches, and employers should find this a useful hands-on manual to help identify the critical employment areas that challenge today's job seekers.

## **Financial Aid for Students with Disabilities in Postsecondary Educational Settings.**

*Rehabilitation Research and Training Center on Blindness and Low Vision, P.O. Drawer 6189, Mississippi State, MS 39762. 120 minutes. ½-inch VHS videotape. \$20.00.*

This videotape is designed to help state VR agencies and other rehabilitation practitioners in securing financial aid for students with disabilities in postsecondary educational settings.



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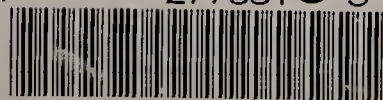




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